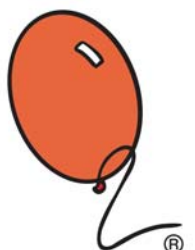


Survey of mesothelioma patients and their carers

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BRITISH LUNG FOUNDATION

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Introduction

Mesothelioma is a terminal chest cancer caused by exposure to asbestos. 2,000 people are diagnosed with Mesothelioma every year, and someone dies of the disease every five hours in the UK.

In 2006 the British Lung Foundation joined together with asbestos support groups, healthcare professionals and families bereaved by the disease to campaign on issues that have an impact on people affected by mesothelioma.

To mark the first Action Mesothelioma Day on 27th February 2006 a 15 point Mesothelioma Charter (see page 4) was presented to 10 Downing Street with more than 14,000 signatures. This Charter outlines the changes and improvements in policy needed to improve the treatment and care of people with mesothelioma and their carers.

For Action Mesothelioma 2009, the British Lung Foundation has conducted a survey of people affected by mesothelioma. This survey represents an attempt to find out how far the targets set out in the Mesothelioma Framework are reflected in the actual experience of patients and carers.

The results give a mixed picture, showing many people receiving excellent care but revealing many other areas for improvement. 84 % of patients reported receiving advice about benefits and compensation, in line with Point 6 of the Charter. However Point 7 of the Charter state that Mesothelioma patients should have access to guidance on End of Life Care - yet our survey reveals that only 25 % of patients report discussing the issue with a medical professional.

The responses from carers also remind us of the distress this disease can cause to those closest to the patients, and of the support that they need. Carers reported higher levels of personal distress than patients, received less guidance and support, and were far less likely to feel well informed throughout the process of diagnosis.

Action Mesothelioma Day represents a chance to celebrate the progress that has been made in mesothelioma care, and to continue to work for improvements. We hope that you will find the results of this survey an enlightening read.

Action Mesothelioma Charter

We, the undersigned, believe that:

Mesothelioma patients and their families have a right to:

1. A speedy and accurate diagnosis, supported by a Multi Disciplinary Team discussion;
2. Good quality information from a variety of sources available in different media and languages;
3. Support of a suitably qualified nurse and other Multi Disciplinary Team members throughout their illness;
4. Be considered for the best possible treatments available with the support and input of a Multi Disciplinary Team;
5. Have up-to-date advice on benefits and help in applying for them, and receive prompt payment of benefits;
6. Have legal advice and guidance from a firm of solicitors experienced in mesothelioma claims;
7. Guidance on end of life decisions and care at home;
8. Provision of a consistent nationwide service from coroners using a clear and open process with a maximum case length of three months.

And call upon the Government to:

9. Have mesothelioma made a national priority by the Cancer Tsar;
10. Fund good quality research, alongside other national bodies, on mesothelioma with a view to improving diagnosis, treatment and outcomes for patients;
11. Support the production of clinical Guidelines on the best practice of diagnosis and management of mesothelioma;
12. Ensure the Health and Safety Executive vigorously enforces existing regulations on asbestos.

And call upon all employers to:

13. Prevent future exposure to asbestos by providing a safe working environment with all necessary equipment to protect employees;
14. Work with unions and individuals to ensure enforcement of current regulations to safeguard all employees;
15. Identify all asbestos in their properties and organise its safe removal where practical or necessary when work is being carried out.

Executive Summary

1. The survey was publicised and distributed by the British Lung Foundation between December 2008 and January 2009. Respondents could complete the survey online or by submitting printed versions. 181 responses were received, 83 of whom were from patients and 98 of whom were from carers.
2. In about three quarters of cases respondents stated that their asbestos exposure had happened at work. Approximately one in twenty were the result of washing a family members clothing.
3. Patients and carers emotional reactions are very different, with far more patients reporting having reached 'peace' than carers.
4. However, 52 % of patients still reported feeling depressed some or most of the time.
5. We asked a series of questions on what support and guidance had been received by patients, in relation to topics such as care of dependents, benefits and compensation, and symptom control
6. On all such questions patients were more likely to have received such support, and were more likely to evaluate the support as good.
7. Some results were good: 86 % of patients had received general support in relation to mesothelioma, and 84 % had received support related to benefits and compensation.
8. However there are considerable areas of concern: just 47 % of patients said that they had received psychological support; only 33 % of patients were given professional support in relation to the needs of dependents, and a mere 25 % of patients had received support in relation to end of life care issues.
9. A detailed collection of questions about specific diagnostic and treatment procedures were asked.
10. 73 % of patients felt well informed throughout the diagnosis process, and 88 % of patients felt that after diagnosis they knew who to contact in the case of difficulties
11. However, 40 % of patients did not believe that their case had been reviewed by a Multi-Disciplinary Team, as the Mesothelioma Charter recommends.
12. Less than 40 % of the patients had been offered the chance to take part in a clinical trial.

Survey Results

Demographics

The survey was publicised by the British Lung Foundation website, Mesothelioma UK, mesothelioma and asbestos support groups, Google ads, posters in hospital wards and in letters to local newspapers in the 'mesothelioma hotspots' . Respondents could complete the survey online or by submitting printed versions. 181 people responded: 83 patients and 98 carers.

The patient group was dominated by men (75 %) and the carer group was dominated by women (87 %) - this is to be expected since Mesothelioma is most commonly contracted by people working in trades which were dominated by men during the period that asbestos was most frequently used. This was reflected in the 114 answers which specified the industries in which patients were exposed to asbestos.

In about three quarters (76.24 %) of cases asbestos exposure had happened in work, and one in twenty (5.56 %) had been exposed through a family members clothing. In 60 % of cases the patients had been diagnosed more than a year before the survey had been completed.

Emotional toll

We asked a series of questions on patients and carers emotional state since diagnosis. The overwhelming majority of patients responded (99% or all but one), and around 90 % of carers did.

Patients and carers emotional reactions tended to be quite different from each other. In general, patients responded more positively and were far more likely to have reached some form of acceptance. 43 % of patients reported having felt 'peace' most of the time since the diagnosis, compared with just 8 % of carers. 79 % of carers felt isolated/alone some or most of the time, compared with 41 % of patients.

This is not to underestimate the emotional burden which the disease puts on patients. 67 % of patients reported feeling anxiety some or most of the time, 59 % reported feeling fear, and 52 % reported feeling depressed.

Support from Healthcare Professionals

We asked survey respondents whether they had received advice and support from healthcare professionals on several different aspects on living with Mesothelioma, and then asked them to rate the quality of the support that they had received. On nearly all questions carers had received less support and advice and were less likely to rate the advice that they did receive as good.

In some respects the results are very positive, with high numbers of patients receiving general information about Mesothelioma, and information about benefits and compensation. However they also indicate a general lack of discussion of many key areas, most notably end of life care.

Information about Mesothelioma:

86 % of patients had received general support in relation to information about Mesothelioma, with 77.63 % rating the support as good. 68 % of Carers had received support, with 60 % of them rating it as good.

Source of Exposure to Asbestos

Patients were asked whether they had received support in relation to the source of their exposure to asbestos. This had been received by 64 % of patients and 52 % of carers. 85 % of patients and 63 % of carers rated the support as good.

Psychological Needs:

Patients reported that they had received support in relation to psychological needs in only 47 % of cases, but in 87 % of cases they rated the support as good. 33 % of carers had received such advice, and 60 % rated the advice as good.

Treatment Options:

Support in relation to treatment options was provided to 81 % of patients, and 89 % rated the support as good. This support was received by 72 % of carers, with 65 % rating it as good.

Benefits and Compensation:

84 % of patients received support in relation to benefits and compensation, and 89 % rated this support as good. 74 % of carers had received such support, and 67 % rated it as good.

Further Advice :

Information on where to go for further advice, including out of hours NHS services, was given to 61 % of patients, 86 % of whom rated it as good. 40 % of carers received such information, 67 % of whom rated it as good.

Symptom Control:

Carers reported that they were provided with professional support in relation to how to control symptoms in 62 % of cases, and rated the support given as good 59 % of the time. Patients reported such support in 53 % of cases, and rated it as good 82 % of the time.

Family and Carers

57 % of patients reported that they had received professional support in relation to family and carers, 83 % of who reported the support as good. 63 % of carers received such support and 63 % of them rated it as good.

Dependents:

Only 33 % of patients were given professional support in relation to the needs of dependents, although 85 % of them rated the advice they received as good. 20 % of carers received such advice, and 70 % felt that it was good.

Palliative Care and End of Life:

Shockingly, only 25 % of patients had received advice in regards to palliative care and end of life support, with 90 % rating the support as good. 62 % of carers had received such support, with 61 % rating it as good.

Diagnosis and Treatment

We asked a series of questions about the process of diagnosis and subsequent healthcare that was provided. Unsurprisingly, carers were far more likely to answer 'not sure' to questions about specific medical treatment than patients. Listed on the following page are the full results given by both patients and carers.

Diagnosis Procedure:

Nearly all patients had a sample of fluid drained from their chests for analysis, and the majority had CT scans. Patients reported a broad range of other diagnostic tools being used. Although 73 % of patients reported that they felt well informed during the diagnosis process this still leaves a large percentage who felt under informed, as did 65 % of carers.

- A CT scan was carried out before diagnosis in 71 % of cases reported by patients and 59 % of cases reported by carers.
- A PET scan was carried out before diagnosis in 5 % of cases reported by patients and 14 % of cases reported by carers.
- A MRI scan was carried out before diagnosis in 18 % of cases reported by patients and 30 % of cases reported by carers.
- A bronchoscopy was carried out before diagnosis in 27 % of cases reported by patients and 30 % of cases reported by carers.
- A sample of fluid was drained from the patients' chest in 92 % of cases reported by patients and 78 % of cases reported by carers.
- A needle biopsy was conducted whilst in a CT scanner before diagnosis in 23 % of cases reported by patients and in 13 % of cases reported by carers.
- A needle biopsy was conducted whilst having an ultrasound in 10 % of cases reported by patients and 9 % of cases reported by carers.
- A needle biopsy was conducted during a chest drain before diagnosis in 25 % of cases reported by patients and 30 % of cases reported by carers.
- A Thoracoscopy was carried out before diagnosis in 31 % of cases reported by patients and in 18 % of cases reported by carers.
- A surgical biopsy with general anaesthetic was carried out before diagnosis in 65 % of cases reported by patients and in 47 % of cases reported by carers.
- 73 % of patients felt well informed throughout the period that investigations were being conducted, compared with 35 % carers.

Looking at this range of responses it is good to note that the vast majority of patients had a sample of fluid taken and a CT scan performed. It is a surprise to see that a MRI scan was used as a diagnostic tool and the range of other tests listed indicate the variety of different procedures used to diagnose mesothelioma.

Treatment

Only 60 % of patients reported that their cases were reviewed by a Multi-Disciplinary Team, a statistic which either reveals that point 4 of the Mesothelioma Charter is not being kept to or that patients are not being adequately informed where it is. Only 40 % of patients had been offered an opportunity to take part in a clinical trial, possibly because there are not enough available.

- 60 % of cases reported by patients and 40 % of cases reported by carers were reviewed by a Multi Disciplinary team.
- Feedback from the review was received by 82 % of patients and 69 % of carers.
- 86 % of patients were clear on who to contact if there were problems and questions, compared with 53 % of carers.
- Only 40 % of patients and only 23 % of carers report being offered the chance to take part in a medical trial.
- Surgery was offered in 40 % of cases reported by patients and in 16 % of cases reported by carers.
- Chemotherapy was offered in 83 % of cases reported by patients and 56 % of cases reported by carers.
- After diagnosis and initial treatment 88 % of patients and 63 % of carers were clear about who to contact in case of difficulties.

Comments from patients and their carers

The survey asked mesothelioma patients and their carers to comment about their experience. Listed below is a selection of these comments:

- 'I was informed that I needed an operation on my lung and that something else was present. They suspected cancer. I was informed that I had Mesothelioma after surgery. Previous to that I had never heard of mesothelioma'
- 'It is essential that frank and comprehensive information is given from the start'
- 'Medical staff at all levels has been and continue to be very caring at all times'

- 'Everyone tried to do all they could to help the situation. Doctors, nurses & staff were really wonderful'
- 'Although devastating I felt my father had a dignified and pain free end to his life'
- 'Palliative care team was never mentioned or referred to, only thoracic team followed by Oncologist and Lung Cancer Specialist Nurse. Family was never informed that coroner would be informed or post mortem carried out, even family GP wasn't sure until after the death and he wasn't sure he could sign death certificate and had to go away to check this out'
- 'The hospital care at the end of my husband's life was poor. Not enough care - no specialised cancer care provided on a general ward that he was placed in'
- 'I have no beneficial comments to make. This whole episode has spoilt whatever years I have left to live'

Further information about mesothelioma

If you have concerns or questions about living with mesothelioma the British Lung Foundation and Mesothelioma UK can provide emotional and practical help.

The British Lung Foundation

Please visit our website www.lunguk.org or phone the British Lung Foundation helpline on 08458 50 50 20

Mesothelioma UK

Please visit the Mesothelioma UK at www.mesothelioma.uk.com or phone 0800 169 2409

Appendix: Full Results

Results: Survey for people affected by mesothelioma (General results)

181 Respondents

1) Which of the following best describes your position?

I have Mesothelioma	83	45.86 %
I care for someone with mesothelioma	24	13.26 %
I have been bereaved by mesothelioma	74	40.88 %

Total = 181

2) Region

Midlands	36	19.89 %
North East	21	11.60 %
North West	29	16.02 %
Northern Ireland	1	0.55 %
Scotland	9	4.97 %
South East	57	31.49 %
South West	27	14.92 %
Wales	1	0.55 %

Total = 181

3) male/female

	Patients	Carers	All
Male	62 (74.70 %)	13 (13.27 %)	75 (41.44 %)
Female	21 (25.30 %)	85 (86.73 %)	106 (58.56 %)
Total	83 (100 %)	98 (100 %)	181 (100 %)

Total: 181

4) How long ago were you/the person you care(d) for diagnosed with mesothelioma?

In the last 6 months	40	20.10 %
Six months to one year	34	18.78 %
More than a year ago	106	58.56 %
No Answer	1	0.55 %

Total: 181

5. Do you know how you/ the person you care(d) for was exposed to asbestos? If so, please give details.

No	33	18.23 %
Through a family member (washing overalls or hugging them when they were in their work clothes)	10	5.52 %
At work	138	76.24 %

Industries they were worked (114 stated where they worked):

- 11 - Refractory bricklayer/Builder
- 2 - Working in a mill II
- 6 - Schools/Universities
- 6 - Chemical Laboratory Work
- 8 - Factory work
- 4 - Pipework and Ducting
- 5 - Amature winder in the meter trade
- 16 - Working in shipyards
- 2 - Lagger
- 1 - Working with scrap metal
- 4 - Mechanic
- 1 - Design engineer
- 6 - Electrician
- 3 - Construction at power stations
- 5 - Painter/Decorator
- 6 - Boiler Engineer
- 9 - Carpenter/joiner
- 2 - Steel works II
- 3 - RAF/ Aircraft industry
- 3 - Plumber
- 1 - National Coal Board
- 1 - Cleaner (Sweeping floors walls and pipes)
- 1 - Sheeter/fitter
- 4 - Rail industry
- 3 - Working for a council
- 1 - Apprentice Draughtsman
- 1 - Maintenance engineer for a large insurance company
- 1 - Navy
- 1 - Gas Industry
- 1 - Demolition Trade
- 2 - Cutting asbestos sheets (as part of job)

6) Since the diagnosis, how often have you felt anger? ** 172 total

	Patients	Carers
Most of the Time	11 (13.25 %)	39 (39.80 %)
Sometimes	27 (32.53 %)	48 (48.98 %)
Rarely	26 (31.33 %)	2 (2.04 %)
Never	19 (22.89 %)	0 (0 %)
N/A	0 (0 %)	9 (9.18 %)
Total	83 (100 %)	98 (100 %)

7) Since the diagnosis, how often do you feel/ have you felt isolated/ alone

	Patients	Carers
Most of the time	2 (2.41 %)	29 (29.59 %)
Sometimes	32 (38.55 %)	48 (48.98 %)
Rarely	25 (30.12 %)	9 (9.18 %)
Never	22 (26.51 %)	4 (4.08 %)
N/a	2 (2.41 %)	8 (8.16 %)
Total	83 (100 %)	98 (100 %)

8) Since the diagnosis, how often do you feel/ have you felt depression/ despair

	Patients	Carers
Most of the time	5 (6.02 %)	27 (27.55 %)
Sometimes	38 (45.73 %)	51 (52.04 %)
Rarely	23 (27.7 %)	9 (9.18 %)
Never	16 (19.28 %)	3 (3.06 %)
no answer	1 (1.20 %)	8 (8.16 %)
Total	83 (100 %)	98 (100 %)

9) Since the diagnosis, how often do you feel/ have you felt fear?

	Patients	Carers
Sometimes	42 (50.60 %)	56 (57.14 %)
Rarely	19 (22.89 %)	9 (9.18 %)
Never	13 (15.66 %)	3 (3.06 %)
Most of the time	7 (8.43 %)	22 (22.45 %)
No answer	1 (1.20 %)	8 (8.16 %)
Total	83 (100 %)	98 (100 %)

10) Since the diagnosis, how often do you feel/ have you felt anxiety?

	Patients	Carers
Most of the time	9 (10.84 %)	37 (37.76 %)
Sometimes	47 (56.63 %)	45 (45.92 %)

Rarely	17 (20.48 %)	6 (6.12 %)
Never	9 (10.84 %)	2 (2.04 %)
Most of the time	9 (10.84 %)	37 (37.76 %)
No answer	1 (1.20 %)	8 (8.16 %)
Total	83 (100 %)	98 (100 %)

11) Since the diagnosis, how often do you feel/ have you felt peace / acceptance

	Patients	Carers
Most of the time	36 (43.37 %)	8 (8.16 %)
Sometimes	23 (27.71 %)	15 (15.31 %)
Rarely	17 (20.48 %)	36 (36.73 %)
Never	6 (7.23 %)	33 (33.67 %)
No answer	1 (1.20 %)	6 (6.12 %)
Total	83 (100 %)	98 (100 %)

12) Was professional healthcare/professional support provided in relation to information about mesothelioma?

	Patients	Carers
Yes	72 (86.75 %)	67 (68.37 %)
No	5 (6.02 %)	23 (23.47 %)
Not sure	6 (7.23 %)	8 (8.16 %)
Total	83 (100 %)	98 (100 %)

13) If yes, please rate the quality of the support provided

	Patients	Carers
Good	59 (77.63 %)	38 (60.32 %)
Average	13 (17.10 %)	17 (26.98 %)
Poor	4 (5.26 %)	7 (11.11 %)
No answer	0 (0.00 %)	1 (1.59 %)
Total	76 (100 %)	63 (100 %)

14) Was professional healthcare and professional support provided in relation to discussion about occupational history and asbestos exposure?

	Patients	Carers
Yes	53 (63.86 %)	51 (52.04 %)
No	18 (21.69 %)	34 (34.69 %)
Not sure	12 (14.46 %)	12 (12.24 %)
No Answer	0 (0 %)	1 (1.02 %)
Total	83 (100 %)	98 (100 %)

15) If yes, please rate the quality of support provided?

	Patients	Carers
Good	45 (84.91 %)	32 (62.75 %)
Average	7 (13.21 %)	17 (33.33 %)
Poor	0 (0 %)	2 (3.92 %)
N/A	1 (1.87 %)	0 (0 %)
Total	53 (100 %)	51 (100 %)

16) Was professional healthcare/ professional support provided in relation to discussion about psychological needs and hopes and fears for the future?

	Patients	Carers
Yes	39 (46.99 %)	32 (32.65 %)
No	32 (38.55 %)	51 (52.04 %)
Not sure	12 (14.46 %)	14 (14.29 %)
N/A	0 (0 %)	1 (1.02 %)
Total	83 (100 %)	98 (100 %)

17) If yes, please rate the quality

	Patients	Carers
Good	34 (87.18 %)	19 (59.38 %)
Average	5 (12.82 %)	9 (29.13 %)
Poor	0 (0 %)	3 (9.38 %)
N/A	0 (0 %)	1 (3.13 %)
Total	39 (100 %)	32 (100 %)

18) Was professional healthcare/ professional support provided in relation to information about treatment options?

	Patients	Carers
Yes	67 (80.72 %)	71 (72.45 %)
No	11 (13.25 %)	20 (20.41 %)
Not sure	5 (6.02 %)	5 (5.10 %)
N/A	0 (0 %)	3 (3.06 %)
Total	83 (100 %)	98 (100 %)

19) If yes, please rate the quality of the support provided

	Patients	Carers
Good	54 (89.60 %)	46 (64.79 %)
Average	8 (11.94 %)	20 (28.17 %)
Poor	3 (4.48 %)	5 (7.04 %)
N/A	2 (2.99 %)	0 (0 %)
Total	67 (100 %)	71 (100 %)

20) Was professional healthcare/ professional support provided in relation to information about benefits & compensation?

	Patients	Carers
Yes	70 (83.74 %)	73 (74.49 %)
No	11 (13.25 %)	18 (18.37 %)
Not sure	1 (1.20 %)	6 (6.12 %)
N/A	1 (1.20 %)	1 (1.02 %)
Total	83 (100 %)	98 (100 %)

21) If yes, please rate the quality of the support provided

	Patients	Carers
Good	62 (88.57 %)	49 (67.12 %)
Average	7 (10 %)	18 (24.66 %)
Poor	1 (1.43 %)	5 (6.85 %)
N/A	0 (0 %)	1 (1.37 %)
Total	70 (100 %)	73 (100 %)

22) Was professional healthcare/ professional support provided in relation to information about where to go for further advice, including out of hours NHS support?

	Patients	Carers
Yes	51 (61.46 %)	39 (39.80 %)
No	23 (27.71 %)	44 (44.90 %)
Not sure	8 (9.64 %)	14 (14.29 %)
N/A	1 (1.20 %)	1 (1.02 %)
Total	83 (100 %)	98 (100%)

23) If yes, please rate the quality of the support provided

	Patients	Carers
Good	44 (86.27 %)	26 (66.67 %)
Average	5 (9.80 %)	9 (23.08 %)
Poor	0 (0 %)	4 (10.26 %)
N/A	2 (3.92 %)	0 (0 %)
Total	51 (100%)	39 (100%)

24) Was professional healthcare/ professional support provided in relation to information on how to control symptoms?

	Patients	Carers
Yes	44 (53.01 %)	61 (62.24 %)

No	26 (31.33 %)	24 (24.50 %)
Not sure	11 (13.25 %)	12 (12.24 %)
N/A	2 (2.41 %)	1 (1.02 %)
Total	83 (100%)	98 (100 %)

25) If yes please rate the quality of the support provided

	Patients	Carers
Good	36 (81.82 %)	36 (59.02 %)
Average	8 (18.18 %)	20 (32.79 %)
Poor	0 (0 %)	5 (8.20 %)
Total	44 (100 %)	61 (100 %)

26) Was professional healthcare/ professional support provided in relation for family and careers?

	Partients	Carers
Yes	47 (56.63 %)	46 (46.94 %)
No	26 (31.33 %)	45 (45.92 %)
Not sure	8 (9.64 %)	6 (6.12 %)
N/A	2 (2.41 %)	1 (1.02 %)
Total	83 (100 %)	98 (100 %)

27) If yes, please rate the quality of the support provided

	Patients	Carers
Good	39 (82.98 %)	29 (63.04 %)
Average	7 (14.89 %)	9 (19.57 %)
Poor	0 (0 %)	6 (13.04 %)
N/A	1 (2.13 %)	2 (4.35 %)
Total	47 (100 %)	46 (100 %)

28) Was professional healthcare/ professional support provided in relation to discussion about the needs of your dependants?

	Patients	Carers
Yes	27 (32.57 %)	20 (20.41 %)
No	46 (55.42 %)	58 (59.18 %)
Not sure	7 (8.43 %)	17 (17.35 %)
N/A	3 (3.61 %)	3 (3.06 %)
Total	83 (100 %)	98 (100%)

29) If yes, please rate the quality of the support provided

	Patients	Carers
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Good	23 (85.19 %)	14 (70 %)
Average	3 (11.11 %)	5 (25 %)
N/A	1 (3.70 %)	1 (5 %)
Total	27 (100%)	20 (100%)

30) Was professional healthcare/ professional support provided in relation to palliative care issues and end of life care?

	Patients	Carers
Yes	21 (25.30 %)	61 (62.24 %)
No	45 (54.22 %)	28 (28.57 %)
Not sure	12 (14.46 %)	8 (8.16 %)
N/A	5 (6.02 %)	1 (1.02 %)
Total	83 (100 %)	98 (100 %)

31) If yes, please rate the quality of the support provided

	Patients	Carers
Good	19 (90.48 %)	37 (60.66 %)
Average	2 (9.52 %)	16 (26.23 %)
Poor	0 (0 %)	7 (11.48 %)
N/A	0 (0 %)	1 (1.64 %)
Total	21 (100 %)	61 (100 %)

32) Have you had support from any other organization or groups?

	Patients	Carers
Yes	49 (57.83 %)	49 (50 %)
No	32 (38.55 %)	47 (47.96 %)
N/A	2 (2.41 %)	2 (2.04 %)
Total	83 (100 %)	98 (100 %)

34) Was a CT scan carried out before a diagnosis of mesothelioma was made?

	Patients	Carers
Yes	59 (71.08 %)	58 (59.18 %)
No	19 (22.89 %)	14 (14.29 %)
Not sure	3 (3.61 %)	24
N/A	2 (2.41 %)	2
Total	83 (100%)	98 (100%)

35) Was a PET scan carried out before diagnosis of mesothelioma was made?

	Patients	Carers
Yes	4 (4.82 %)	14 (14.29 %)
No	49 (59.04 %)	34 (34.69 %)
Not sure	24 (28.92 %)	47 (47.95 %)
N/A	6 (7.23 %)	3 (3.06 %)
Total	83 (100 %)	98 (100 %)

36) Was an MRI scan carried out before a diagnosis of mesothelioma was made?

	Patients	Carers
Yes	15 (18.07 %)	29 (29.59 %)
No	50 (60.24 %)	35 (35.71 %)
Not sure	15 (18.07 %)	33 (33.67 %)
N/A	3 (3.61 %)	1 (1.02 %)
Total	83 (100 %)	98 (100 %)

37) Was a Bronchoscopy carried out before diagnosis of mesothelioma was made?

	Patients	Carers
Yes	22 (26.51 %)	29 (29.59 %)
No	48 (57.83 %)	44 (44.90 %)
Not sure	10 (10.05 %)	33 (33.67 %)
N/A	3 (3.61 %)	2 (2.04 %)
Total	83 (100 %)	98 (100 %)

38) Was a sample of fluid drained from your chest and sent for analysis before a diagnosis of mesothelioma was made?

	Patients	Carers
Yes	76 (91.57 %)	76 (77.55 %)
No	5 (6.02 %)	11 (11.22 %)
Not sure	1 (1.20 %)	9 (9.18 %)
N/A	1 (1.20 %)	2 (2.04 %)
Total	83 (100 %)	98 (100 %)

39) Were you given a needle biopsy whilst in the CT scanner before a diagnosis of mesothelioma was made?

	Patients	Carers
Yes	19 (22.89 %)	13 (13.27 %)
No	50 (60.24 %)	33 (33.67 %)
Not sure	8 (9.64 %)	12 (12.24 %)
Don't know	3 (3.61 %)	38 (38.78 %)

N/A	3 (3.61 %)	2 (2.04 %)
Total	83 (100 %)	98 (100 %)

40) Were you given a needle biopsy whilst having an ultrasound before a diagnosis of mesothelioma was made?

	Patients	Carers
Yes	8 (9.64 %)	9 (9.18 %)
No	63 (75.90 %)	35 (35.71 %)
Not sure	8 (9.64 %)	10 (10.20 %)
Don't Know	2 (2.41 %)	42 (42.86 %)
N/A	2 (2.41 %)	2 (2.04 %)
Total	83 (100 %)	98 (100 %)

41) Was a needle biopsy taken on the ward during a chest drain before diagnosis of mesothelioma was made?

	Patients	Carers
Yes	21 (25.30 %)	29 (29.59 %)
No	42 (50.60 %)	24 (24.49 %)
Not sure	16 (19.28 %)	42 (42.86 %)
N/A	4 (4.82 %)	3 (3.06 %)
Total	83 (100 %)	98 (100 %)

42) Was a thoracoscopy carried out before a diagnosis of mesothelioma was made?

	Patients	Carers
Yes	26 (31.33 %)	18 (18.37 %)
No	30 (36.14 %)	26 (26.53 %)
Not sure	25 (30.12 %)	52 (53.06 %)
N/A	2 (2.41 %)	2 (2.04 %)
Total	83 (100 %)	98 (100 %)

43) Was a surgical biopsy with general anaesthetic carried out before a diagnosis of mesothelioma was made?

	Patients	Carers
Yes	54 (65.06 %)	46 (46.94 %)
No	25 (30.12 %)	34 (34.69 %)
Not sure	4 (4.82 %)	16 (16.33 %)
N/A	0 (0 %)	2 (2.04 %)
Total	83 (100 %)	98 (100 %)

44) Did you feel well informed throughout the time investigations were being carried out and given?

	Patients	Carers
Yes	61 (73.49 %)	34 (34.69 %)
No	16 (19.28 %)	51 (52.04 %)
Not sure	6 (7.23 %)	11 (11.22 %)
N/A	0 (0 %)	2 (2.04 %)
Total	83 (100 %)	98 (100%)

45) Was your case reviewed by a multidisciplinary team?

	Patients	Carers
Yes	50 (60.24 %)	39 (39.80 %)
No	7 (8.43 %)	14 (14.29 %)
Not sure	25 (30.12 %)	44 (44.90 %)
N/A	1 (1.20 %)	1 (1.02 %)
Total	83 (100 %)	98 (100 %)

46) If so, did you receive feedback from this review?

	Patients	Carers
Yes	41 (82 %)	27 (69.23 %)
No	4 (8 %)	12 (30.76 %)
Not sure	5 (10 %)	0 (0 %)
Total	50 (100 %)	39 (100%)

47) If problems or questions arose during investigations or treatment were you clear about who to contact in hospital?

	Patients	Carers
Yes	71 (85.54 %)	52 (53.06 %)
No	9 (10.84 %)	32 (32.65 %)
Not sure	3 (3.61 %)	12 (12.24 %)
N/A	0 (0 %)	2 (2.04 %)
Total	83 (100 %)	98 (100 %)

48) Were you offered a chance to take part in a medical trial?

	Patients	Carers
Yes	33 (39.76 %)	23 (23.47 %)
No	43 (51.81 %)	64 (65.31 %)
Not sure	7 (8.43 %)	9 (9.18 %)
N/A	0 (0 %)	2 (2.04 %)
Total	83 (100 %)	98 (100 %)

49) Was surgery offered?

	Patients	Carers
Yes	33 (39.76 %)	16 (16.33 %)
No	47 (56.63 %)	74 (75.51 %)
Not sure	3 (3.61 %)	6 (6.12 %)
N/A	0 (0 %)	2 (2.04 %)
Total	83 (100 %)	98 (100 %)

50) Was chemotherapy offered?

	Patients	Carers
Yes	69 (83.13 %)	55 (56.12 %)
No	13 (15.66 %)	35 (35.71 %)
Not sure	0 (0 %)	6 (6.12 %)
N/A	1 (1.20 %)	2 (2.04 %)
Total	83 (100 %)	98 (100 %)

51) Once the investigations and initial treatment were completed were you clear about who to contact if you had questions or difficulties?

	Patients	Carers
Yes	73 (87.95 %)	61 (62.24 %)
No	7 (8.43 %)	21 (21.43 %)
Not sure	3 (3.61 %)	14 (14.29 %)
N/A	0 (0 %)	2 (2.04 %)
Total	83 (100%)	98 (100 %)