



**MESOTHELIOMA UK**

Mesothelioma UK  
National Mesothelioma Experience Survey  
2012

---

**patient**  
PERSPECTIVE

## EXECUTIVE SUMMARY

- 652 patients and carers **responded to the survey**, carried out between December 2011 and April 2012.
- **Overall experiences of care** varied widely from “wonderful” to “barbaric”.
- Nearly 20% of responders **saw their GP five or more times** before being referred to a hospital specialist.
- Many responders commented that **GPs should have more training** in recognising the signs and symptoms of mesothelioma.
- About 50% did not fully **understand their diagnosis** when they were first told about it.
- 34% of responders felt that their **diagnosis could have been explained more sensitively**.
- At diagnosis, 30% did not receive **written information** about mesothelioma.
- Over 36% would have liked more **involvement in making decisions** about their care.
- Several people commented that **variations in the care** available to patients in different geographical locations were unfair.
- Just under 50% thought that their **outpatients appointments** were not frequent enough.
- Just over 50% said that **doctors “always” gave understandable answers** to their questions, and several commented positively on doctors’ willingness to respond to their questions.
- 40% said they were **told different things** by different doctors and nurses.
- Around 27% thought **doctors treating them did not know enough** about mesothelioma.
- 88% were given the name of a **Clinical Nurse Specialist** and many positive comments were made about the specialist nurses.
- Just under 50% felt they were **not given emotional support** in dealing with mesothelioma.
- 71% said they were given information about self-help and **support groups**. Many said they found support groups very helpful, and many mentioned Mesothelioma UK.
- About 50% would have liked more **support at home** (such as home helps or district nurses).
- Almost all responders got the information they needed about getting **financial help**.
- Many comments about **Macmillan nurses** were very positive, but there were a fairly high number of negative comments about Macmillan nurses.
- Most thought their **care was well co-ordinated** between different organisations, but several found a lack of communication between organisations, which caused them distress.
- 55% of responders said they *definitely* received good **support from their GP and community nurses**, and there were many positive comments about GPs and community nurses.

## TABLE OF CONTENTS

Introduction.....	4
1 Survey method .....	4
2 Who completed the survey? .....	6
3 Overall experiences of care .....	7
4 Asbestos exposure.....	8
5 Getting a hospital referral from the GP.....	9
6 Diagnostic tests .....	10
7 Being given a diagnosis.....	11
8 Treatment information and choices.....	13
9 Speed of receiving treatment.....	15
10 Order in which treatments were given .....	15
11 Surgery .....	15
12 Chemotherapy.....	16
13 Radiotherapy .....	17
14 Hospital outpatients appointments .....	17
15 Hospital inpatient care .....	18
16 Clinical Nurse Specialists .....	21
17 Emotional support.....	22
18 Self-help and support groups .....	22
19 Support at home.....	23
20 Planning end-of-life care .....	24
21 Palliative care .....	24
22 Co-ordination of care .....	26
23 GPs and community nurses.....	27
24 Legal matters.....	28
25 More funding for research .....	28
Acknowledgements.....	30
Contact Details for Mesothelioma UK.....	31
Appendix – Full tables of survey responses .....	32

## Introduction

Mesothelioma UK is a national resource centre dedicated to providing specialist Mesothelioma information, support & improved care and treatment. Mesothelioma UK commissioned Patient Perspective to conduct this survey to give mesothelioma patients, carers and those bereaved an opportunity to describe their experiences.

Patient Perspective is a specialist provider of patient surveys and is approved by the Care Quality Commission (CQC) to conduct patient surveys and report the findings.

It is hoped that this survey will enable Mesothelioma UK to inform healthcare providers what is being done well, what could be improved and demonstrate where there are variations in care, as well as helping Mesothelioma UK to develop its services to complement those of the NHS. Mesothelioma UK will make recommendations representing the patient experience and widely circulate these to the mesothelioma community and healthcare providers.

## 1 Survey method

### Topics covered

The self-completion survey comprised 79 “closed” questions, for which patients were asked to choose a response option. The topics covered included patients’ experiences of:

- Care from their general practice
- Diagnostic tests
- Being given a diagnosis
- Support at home
- Information to support patients to cope at home
- End-of-life care
- Financial and legal support
- Treatment options
- Information on treatments and side effects
- Outpatients’ appointments
- Care from doctors and nurses in hospital and some demographic questions.

In addition, patients were invited to add their own comments in three “open” questions:

- Is there anything particularly good about the care and treatment of mesothelioma you would like to add?
- Is there anything that could be improved about the care and treatment of mesothelioma?
- Any other comments?

Where possible, those comments have been included within this report in the relevant section of the survey report.

## Invitations to participate

The survey was conducted via the internet and by post. Responses were received between 17th December 2011 and 30<sup>th</sup> April 2012. Mesothelioma patients and their carers were invited to take part through the following channels:

- Advertisements in the Mesothelioma UK quarterly newsletter
- On the home page of the Mesothelioma UK website [www.mesothelioma.uk.com](http://www.mesothelioma.uk.com), the following notice:

**National Mesothelioma Experience Survey** - Mesothelioma UK would like to give mesothelioma patients, carers and those bereaved the opportunity to describe what their experience has really been like. Please click here for the [online survey](#) - alternatively you can call the Helpline on 0800 169 2409 or email [mesothelioma.uk@uhl-tr.nhs.uk](mailto:mesothelioma.uk@uhl-tr.nhs.uk) for a copy to be posted to you. Thank you.

- Paper copies of the questionnaire (with Freepost return envelopes) were distributed by specialist nurses and other healthcare professionals from the following groups:
  - National Lung Cancer Forum for Nurses members (NLCFN)
  - Mesothelioma Nurse Action Team (M-NAT)
  - British Thoracic Oncology Group (BTOG)
- Asbestos support groups and patient groups (including the Mesothelioma Warriors) were also asked to circulate information about the survey to their members and contacts.

## Data Collection

Data from internet and postal responses were collated and analysed by *Patient Perspective*, an independent survey company which specialises in conducting patient surveys for NHS, independent and third sector healthcare organisations in the UK.

## 2 Who completed the survey?

Of the 652<sup>1</sup> surveys received, 42% were mesothelioma patients, 24% were current carers, partners or relatives of the person with mesothelioma and 34% were carers, partners or relatives of people who had died of mesothelioma.

Who is completing the survey?	Number of responders	%
The person with mesothelioma	272	42.3
The carer/ partner/ relative of the person with mesothelioma	153	23.8
The bereaved carer/ partner/ relative of the person with mesothelioma	218	33.9
<b>Total</b>	<b>643</b>	<b>100.0</b>

### Age and gender

The majority of responders were aged between 51 and 85 years, and only a few were older or younger. Most patients (80%) were male.

	Age group when mesothelioma was diagnosed by gender							Total (%)
	16-25	26-35	36-50	51-65	66-75	76-85	86 +	
<b>Male</b>	0	2	10	158	190	78	7	<b>445 (80.3%)</b>
<b>Female</b>	0	0	18	36	37	17	1	<b>109 (19.7%)</b>
<b>Total (%)</b>	<b>0 (0.0%)</b>	<b>2 (0.4%)</b>	<b>28 (5.1%)</b>	<b>194 (35.0%)</b>	<b>227 (41.0%)</b>	<b>95 (17.1%)</b>	<b>8 (1.4%)</b>	<b>554 (100%)</b>

<sup>1</sup> Totals in the tables in this report may be lower than the total 652 surveys received because not all responders answered all questions. Percentage results given are based on the number of responders that answered each question – missing responses are not included in the calculation of percentage results for each question. The number of missing responses for each question is shown in the Appendix.

## Time since diagnosis

Forty-nine per cent of the responders were diagnosed in the last 12 months.

How long ago was Mesothelioma diagnosed?	Number of responders	%
In the last 6 months	160	29.0
In the last 6 to 12 months	108	19.6
More than 1 year ago	101	18.3
More than 2 years ago	78	14.1
More than 3 years ago	105	19.0
<b>Total</b>	<b>552</b>	<b>100.0</b>

## Type of mesothelioma

Almost all responders had pleural mesothelioma; only 4% had peritoneal mesothelioma.

What type of Mesothelioma was diagnosed?	Number of responders	%
Pleural (chest)	524	96.0
Peritoneal (abdomen)	22	4.0
<b>Total</b>	<b>546</b>	<b>100.0</b>

## Region

Responses were received in good numbers from all regions of England. There were also fairly good response numbers from Scotland, but few from Wales or Northern Ireland.

Which region does the patient live in?	Number of responders	%
North East England	68	12.3
North West England	62	11.2
Midlands	114	20.7
South East England	172	31.2
South West England	55	10.0
Scotland	58	10.5
Wales	19	3.4
Northern Ireland	4	.7
<b>Total</b>	<b>552</b>	<b>100.0</b>

## 3 Overall experiences of care

Responders' comments about their overall care revealed very wide variations in their experiences. Some were very positive:

*I have received extraordinary care so far and could not thank the people looking after me enough for all they have done. The army of professionals looking after me always try their very best in all regards.*

*I have been treated as if I am the only person with mesothelioma. People do care and being treated as an individual was a good morale booster.*

*I owe all the staff concerned a debt of gratitude for the two years my wife and I had together from diagnosis to her sadly passing away.*

Others were very negative:

*The process from diagnosis to death was only 8 weeks, it was traumatic, cruel and barbaric. The medical profession were in most cases incompetent at [\*\*\*] and the Macmillan nurse was dreadful. We were very traumatised by their handling of this dreadful disease that took us by surprise and shock like a bolt out of the blue.*

*Meso is extremely frightening. It is the Horror Disease.*

*I found the "health professionals" to be anything but professional and the care to be shockingly poor.*

*I feel like I've been left and no treatment. I've had to fight just to get an appointment. I really feel I've been left out.*

## 4 Asbestos exposure

### Did anyone help patients identify the source of Mesothelioma?

Around the time of being diagnosed with Mesothelioma, 44% of the responders felt that they already knew where their asbestos exposure had occurred. Forty per cent were helped to identify the source of the exposure (13% by a doctor or nurse, 11% by a support group and 16% by *someone else*), and 17% said they were not helped to identify where the exposure had occurred. Most of those who added a comment identifying the "someone else" who had helped them said "solicitor" or "lawyer".

### Had patients previously been diagnosed with any other asbestos-related diseases?

Most responders (81%) had *not* been diagnosed with any other asbestos-related diseases before being diagnosed with mesothelioma, but 7% had been diagnosed with pleural plaques, 6% with pleural thickening and 1% with asbestosis. Most responders (80%) had *not* worried about asbestos-related disease before being diagnosed, but 12% said they had *always* worried about it and 8% said they had worried about it *recently*.

### Asbestos and mesothelioma awareness

Several responders commented that the dangers of asbestos should be publicised more, or that there should be more public information on mesothelioma.

*Highlight dangers and deaths caused by asbestos!*

*More awareness as meso is now becoming a major worry and concern for those of us that have it and for those who might get it.*

*There should be more done to make the general public aware of the dangers of asbestos.*



One person thought there should be mesothelioma screening in areas of high risk.

*So many men who have worked hard all their lives are suffering in silence. We live in a 'cluster' area for meso, due to so many men working in the local power station. Yet there is still no screening programme.*

## 5 Getting a hospital referral from the GP

Fifty-one per cent of responders saw their GP once or twice before being referred to a hospital doctor, while 10% did not see their GP at all before they were examined or treated for mesothelioma in a hospital. Twenty per cent of responders had three or four GP appointments for their mesothelioma-related health problems before being referred for a hospital appointment, and 19% had five or more appointments. For some patients, their GP had been quick to refer the patient:

*My husband's GP was very quick to pick up the fact that he was not producing sputum with the cough he had and quickly sent him to hospital for an x-ray, after which things moved very quickly.*

However, others felt that their GP had been too slow to notice that their symptoms required further investigation:

*It took a year to diagnose, after that I cannot fault the care and treatment I received.*

*Took GP several visits and four months to get me an x-ray to investigate pain.*

*Much earlier diagnoses. It was 9 months from the onset of symptoms before a diagnosis was made. GP was treating him for muscle strain.*

*GPs should be aware that patients with persistent cough and other treatments not curing it should be sent for chest x-ray. This patient died 3 weeks after lung finally collapsed and 3 days after diagnosis of mesothelioma.*

*Unfortunately it took nearly a year for my late husband's mesothelioma to be diagnosed.*

*My wife went to her GP for approximately 5 years with back pain. Diagnosed as arthritis, rheumatism, virus.*

Several responders said they thought GPs need more training in recognising the signs and symptoms of mesothelioma.

*More training and awareness should be given to GPs and accident and emergency doctors about symptoms for mesothelioma as they appeared unaware as on a number of occasions said the pain my late mother was in was caused by a cracked rib or muscle strain and referred her for physiotherapy or x-rays. Even when the x-ray showed dark patches on her lungs they said it was just the shadow off of her shoulder. It took six months before a diagnosis was made.*

*I think there could be more information given to GPs. i.e. asking about asbestos contact when patient comes to them with breathing difficulties/pain.*

*GPs still need more education about Mesothelioma because often do not have many patients to see with this condition they seem reluctant to attend seminars, etc.*

*GP not knowledgeable about the disease or EPP operation. Other departments like A&E were not aware of the disease. Could do with better emergency admissions for mesothelioma patients.*

*GPs need better training. For over a year my husband was told it was indigestion. It wasn't until I went with him that we found out what it was. He died 7 weeks later.*

*More information needs to be given to GPs about the seriousness of this disease and how quickly it can progress and how debilitating it can be to the sufferer.*

## 6 Diagnostic tests

### Distance travelled for tests

Most (64%) of responders said that all of their diagnostic tests were carried out at their local hospital, but the remainder (36%) had to go to another hospital for at least some of their tests. For those who had to travel for some of their tests, 20% travelled less than 10 miles, 38% travelled 11-25 miles, 27% travelled 26-50 miles and 15% travelled more than 50 miles. Overall, only 14% *mind*ed about the distance they had to travel for their tests, with those who had to travel further minding it more than those who only had to travel short distances.

### Diagnostic tests patients had undergone

Patients each had an average of two to three tests. A few (8%) said they had had none of the 13 tests listed and one person said they had nine of the tests. The most common tests were *CT scan*, which 66% of patients had undergone, followed by *Sample of the fluid from lung drained for tests* (60%), *surgical biopsy with general anaesthetic* (34%) and *Needle biopsy while being scanned* (23%). A few responders (7%) said they had undergone tests that were not among the 13 listed. Of the “Other” responses, the most common response was *x-ray* (27 responders), followed by *Ultrasound* (6 responders).

When asked specifically about the number of times fluid had been drained, 16% of responders said they had never had fluid drained, 38% said fluid had been drained once, 37% had had fluid drained two to four times and 9% had had fluid drained five or more times.

### Information about diagnostic tests

Regarding information about tests, 49% said that had *definitely* been provided before the tests were conducted, while 38% said such information had been provided *to some extent*, but 13% said they had not been given information about their tests prior to them being conducted.

Similarly, nearly 47% said they found information about tests *easy to understand*, 44% said they understood it *to some extent*, and 9% did *not* find it easy to understand.

A cross-tabulation of those who said “No” (information about tests had not been provided) by the tests they said they had had suggests that those who said they had a *sample of fluid drained from the abdomen* or *Laparoscopy* were most likely to say they were *not* given information prior to tests, but this finding must be interpreted with caution, since most patients had more than one test and it is not possible to identify which tests they are referring to when they responded to the information question.

### Time taken to diagnose Mesothelioma

Several responders’ comments indicated that they felt that it had taken too long for Mesothelioma to be diagnosed.

*Dad's official diagnosis only came three days before he died. It took more than seven weeks for official diagnosis to come through.*

*Doctor could have been more receptive to the possibility that women can develop mesothelioma.*

*Very late diagnosis, specialists that weren't open minded, and 'wrote off' my father very quickly.*

## 7 Being given a diagnosis

### Who told the patient the diagnosis?

Most patients (86%) heard the news that they had mesothelioma from a doctor. A few (3%) were told by a hospital nurse and 3% were told by a GP. The remaining 8% were told by a friend or relative, "someone else" (4%), or they worked it out for themselves.

Of those who said *someone else* had told them, the largest number (22 responders) said that a type of doctor (such as "consultant", "surgeon" or "oncologist") had told them.

Some relatives received the news only after the patient's death.

*It was only after death, our GP urgently requested the results of the tests that a post-mortem was carried out. The inquest revealed it was mesothelioma.*

Another two patients seemed to have received the news indirectly:

*A letter from the hospital to the GP, patient cc'd in  
Appointment for oncology arrived.*

### Understanding the diagnosis

Fifty-five per cent of the responders said that their diagnosis was given in an understandable way, but 36% said it was only understandable only *to some extent* and 8% said it was *not* given in an understandable way.

### Sensitivity of the person giving the diagnosis

About two-thirds (66%) of the responders said that their diagnosis was given to them sensitively.

*The shock of finding out was helped by the sensitivity of all hospital staff.*

However, 19% thought it could have been given *a bit more sensitively* and 16% thought it could have been done *a lot more sensitively*. Comments on the sensitivity of the people giving the diagnosis varied widely:

*The hospital registrar, who was young to have achieved his position, was clearly proud of his achievement and of his expertise in diagnosing the asbestos related illness and could, I'm sure, be relied upon for clinical excellence. However, I couldn't help feeling his ability to communicate tenderness and empathy could find room for improvement.*

*We all know that mesothelioma has no known cure and is terminal, but this is sometimes the last thing the patient needs rammed down their throats. We all want to live in hope! Patients often feel as though they are a 'lost cause' with no hope. This is so wrong. Senior consultants seem to be the worst offenders.*

*My dad overheard nursing staff giving him "six months at most" when he was diagnosed.*

*Following a check up by a doctor at the day care centre, my husband was advised to prepare his funeral arrangements. He was so traumatised. He demanded to be taken home right away, instead of waiting for the usual arrangement to be returned home. I was angry because he is such a patient, stoic person. I said let's both make these arrangements now (because I had not) and then get on with our lives! Which we did.*

Several patients and their carers said they felt abandoned immediately after they had been given the diagnosis, with no support from health professionals.

*At the time of diagnosis my wife and I were left from Friday pm until Monday without ANY support or care. We had no inclination I had mesothelioma and felt badly let down by the lack of support or care. The surgeon who diagnosed my mesothelioma should attend a course in doctor-patient liaison!! He was abrupt and could not wait to depart quick enough.*

*The first 72 hours after diagnosis are by far the hardest to come to grips with. I feel there needs to be much more psychological support at this crucial time.*

## Getting a second opinion

Sixteen per cent of patients said they were given information about getting a second opinion about mesothelioma or its treatment. Some comments described the support patients received from their local hospital doctors in getting other medical opinions and treatment from other specialists.

*I have a really good oncologist who has been more than happy to provide CT scans to forward to specialist in States, also happy to refer me to other specialist in Britain for further treatment if possible.*

*My oncologist at my local hospital has been really good and happy to provide scan CD to send to the States re other treatment. Also to refer me to a specialist "up north" re other treatment.*

However, others had sought second opinions without the support of their local consultant.

*After my research on the internet, I arranged a second opinion. This was all my own work as I felt a lack of support and information after diagnosis. From a poor start with support and care, I now feel it is improving.*

*My husband was unfortunate enough to get a registrar who was not interested in him, when we told her we were opting for chemoembolisation in Germany she totally lost interest in anything to do with my husband, so much so that we made a formal complaint about her, she would not give us answers to our questions or information that we required to make decisions.*

Several responders had positive experiences of their by treatment specialists at other NHS Trusts

*I found out about Dr. [\*\*] at [\*\*\* NHS Trust], he is tremendous and our local consultant is now willing to work with him and things have improved.*

*Our family researched and went to Dr. [\*\*] at [\*\*\* NHS Trust] and him and his team gave us the hope and encouragement and support every patient deserves.*

*I found Dr. [\*\*] via the internet and the Mesothelioma Research Foundation in the States. We went to see Dr [\*\*\*] when the tumour returned following chemo. He then tried radio ablation therapy and then chemo-embolisation which extended my brother's life.*

*The team at [\*\*\* NHS Trust] have been very good at providing better analysis of evaluation of tests (scans etc) and discussing options for treatment.*

*We were told there was no effective chemotherapy. I researched this myself and found that [drug name] had been developed and had been found to extend life. It was not available in the North East on the NHS but my son contacted a doctor in London at [\*\*\* NHS Trust] who agreed to treat my husband. His treatment in London was excellent. The doctors there seemed much more knowledgeable about Mesothelioma than doctors here in the N.E.*

*My brother received excellent care at Basingstoke following surgery by Mr [\*\*]. However we, as a family, had to find Mr [\*\*] who is an expert in the field. Our local hospital told us that the tumours were INSIDE the liver and that they could do nothing more! Luckily we got to see Mr [\*\*] who did a scan to show the tumours were OUTSIDE the liver and said he could operate.*

## 8 Treatment information and choices

### Written information about diagnosis

About two-thirds (67%) said they received written information about mesothelioma, but 30% did not receive written information. (The remaining 3% said they did not need written information). Of those who received written information, only 41% said it was *very easy* to understand, while 48% said it was *fairly easy* to understand, 8% said it was *not very easy* and 4% said it was *not at all easy* to understand the written information they were given.

*From the first diagnosis, which my husband was told by himself, there has been a very disjointed level of information and care. I have found out relevant information on line by myself. I feel there needs to be a more comprehensive pack of information with regard to benefits, help lines, causes, effects and care in order to make this difficult journey easier.*

One comment indicated that they would have preferred *less* written information:

*Too many brochures and booklets given, as an easy alternative to personal information and help.*

### Written information about treatment and side effects

Most patients (62%) said they had been given easy-to-understand information about their treatment and its side effects, but 11% said the written information they were given was *not easy to understand*, and 28% said they were *not* given written information about treatments.

### Involvement in treatment decisions

Of those patients for whom more than one treatment was possible, 63% said they were *definitely* involved as much as they wanted to be in decisions about which treatment to have.

*The support provided by the team at the [\*\*] Unit at [\*\*\*] Hospital was excellent. My partner was treated as a person and then a patient. It was so important. He was involved at each decision.*

*Oncologist /specialist lung nurse both excellent. Accepted that we researched treatment options on the internet and listened to our views.*

However, 26% said they were only involved *to some extent* and 10% said they would have like to have been more involved in deciding which treatment to have.

*Decision and choice of management and relevant surgeries applicable to condition not discussed at the time of diagnosis. Very poor patient involvement in treatment as per "The white paper" 2011.*

Some felt they needed more support to make a decision:

*I found it very difficult to make the decision about whether or not to have chemotherapy and the health professionals couldn't guide me to a decision.*

Others felt that doctors were not interested in the patient's views on treatment options.

*My husband was given one dose of chemo and as he was so ill after for 2 weeks, and actually had to be rushed to hospital with dehydration, he decided not to have any more. The chemo Dr said it may extend his life by 3 months but he said it wasn't worth it. I felt this Dr. tried to force him to change his mind and I had to insist that my husband had thought about it. I felt the Dr. should have talked calmly and with understanding, which he didn't.*

*One Professor ignored what my dad said to him and tried to bully him into a treatment that would have done him no good what so ever. Why can't doctors listen to what information families have?*

## **Clinical trials**

About a third of patients (34%) were given information about participating in a clinical trial, but 66% did not. Others found it difficult to get the information about trials that they wanted.

*I would like to have more info of current trials or techniques which are evolving.*

*It is also very difficult to get a central view of all the possible trials available, so a centralised database would be good.*

*More information regarding clinical trials [is needed].*

Others felt that their consultant was not positive about trials:

*Unfortunately our oncologist is very dismissive of mesothelioma patients and possible trials. We know this isn't the case everywhere and thank heavens for the online help we have found.*

## **Alternative therapies and holistic care**

Some responders felt that NHS doctors were not open to the possible benefits of alternative therapies.

*There is a lack of coordination between mainstream treatment to alternative therapies which could help the patient. We found The Cancer Active Site most useful, post Rainbow diet, homeopathy for the cough (which was stopped) etc.*

Some commented that a more holistic approach to care was needed.

*Only a few doctors were interested in his health and quality of life together. The rest only wanted my dad pumped full of drugs.*

*Rely less on surgery, chemotherapy, and radiation which ultimately weaken the immune system.*

## **Geographical variations**

Several people commented that the treatment options offered to patients varied by where they lived, and that they found this unfair.

*Because we live a long way from other specialist hospitals we are disadvantaged when it comes to travelling to take part in trials or receiving care from other centres of excellence. Oncologist agreed to give [\*\*] in NHS hospital with patient paying for drug privately and hospital bureaucracy stopped this minutes before its administration. Our loved one could have survived longer if this didn't happen.*

*Care and treatment quality varies considerably until Meso UK is involved. Is there any way of getting awareness of Meso UK to people as soon as they are diagnosed?*

*Any new drugs should be available to everyone who would benefit. It was devastating to find out there was an effective drug that wasn't available to us! My husband campaigned tirelessly to get this drug available on the NHS, even though he was extremely ill. This should never have been necessary!*

*More precise treatment and not to do with where you live.*

*Had my treatment in a specialised thoracic centre locally and had a thoracic surgeon with a lot of experience. Feel others not so lucky if live in different geographical locations.*

## 9 Speed of receiving treatment

Some responders were pleased that they had been treated quickly.

*Once diagnosed, treatment began very quickly. Hospital staff, especially the nurses, were very caring and professional.*

*In my case very quick, not many days waiting.*

Others felt there had been unnecessary delays in starting their treatment

*Primary care service were not responsive enough and could not manage the speed of deterioration. Need to get PCT approval for surgical intervention took too long and caused additional and unnecessary stress.*

## 10 Order in which treatments were given

Surgery was most often offered as the first type of treatment for mesothelioma, followed by Chemotherapy and Radiotherapy. Of those who received Radiotherapy, about 50% had previously also had surgery or undergone radiotherapy.

Age group when mesothelioma was diagnosed by gender

Was this the first, second or third type of treatment for Mesothelioma?	Surgery	Chemotherapy	Radiotherapy
First	82.7	60.7	48.7
Second	13.2	28.5	34.5
Third	4.1	10.8	16.8

## 11 Surgery

Just over a third of patients (36%) underwent surgery as part of their treatment. Of those who had surgery, for most (83%) it had been the first type of treatment they had undergone.

### Explanation beforehand

Of those that had surgery, 77% said a member of staff had explained *completely* what would be done during the operation, while for 21% it had been explained *to some extent* and only 2% said their operation had *not* been explained beforehand.

## Written information before the operation

Fifty-eight percent of those who had surgery said they were given *easy-to-understand written information* about it beforehand, while 8% said the written information they received was *difficult to understand* and 34% said they were *not given any* written information about their operation beforehand.

## Being told how the operation had gone

Of those who had surgery, 51% were told how it had gone in an understandable way, but 37% were only told this information *to some extent* and 11% were *not* given an explanation of how the operation had gone *but would have liked it*.

One responder described a negative experience of being told how the operation had gone:

*The registrar that came to see my husband after he had been to theatre, beat about the bush and was far too technical about what had taken place in theatre. Also, the surgeon the previous evening had led my husband to believe that he could sort out the problem and that it was unlikely to be mesothelioma. I had the unenviable task of telling my husband that he did have it.*

## 12 Chemotherapy

Nearly two thirds (63%) of patients had chemotherapy as part of their treatment and, of those, it was the first type of treatment given for 61%.

Some patients had overall positive comments to make about their experience of chemotherapy:

*Although chemotherapy was difficult for my mother to endure it did extend her life. This would not have been possible without the fantastic kind and awareness raising of the Mick Knighton Mesothelioma Research Fund.*

*Just thankful that the chemotherapy fairly soon after diagnosis bought my husband some extra time.*

Others were less positive:

*The effects of chemotherapy were terrible and eroded all quality of life. In the end, it was not worth all the suffering.*

*I have very mixed feelings about the desirability of chemotherapy. At the time, we were desperate to try anything, but I'm not sure we realised how dreadful the side-effects might be. With hindsight, I wish Dad hadn't had the chemo, because I doubt it extended his life much, but certainly adversely affected the quality of it. I feel the prevailing philosophy was weighted strongly in favour of treatment, even though it might not necessarily have been in the patient's best interests. I wish there had been a fuller exploration of the virtues of "conservative" treatment, without radical chemo.*

## Explanation of chemotherapy side effects

More than two thirds (70%) of those who had chemotherapy said that the possible side effects were *definitely* explained to them, but 28% said the side effects were only explained *to some extent* and 2% said they were *not explained*.

*I had an informative pre chemo meeting when everything was explained to me.*

However, 28% said they were given this information *to some extent*, and just 2% said side effects were *not* explained.



*The doctors and nurses should have more information about side effects and what to do and take which could ease these.*

*More discussion of side effects and their treatment - e.g. what's common (sore oesophagus)*

### **Control of chemotherapy side effects**

Most patients (75%) felt that hospital staff *did everything possible* to control the side effects of chemotherapy, but 19% felt this was true only *to some extent* and 6% felt staff *could have done more* to control chemotherapy side effects.

## **13 Radiotherapy**

Forty-three per cent of patients had radiotherapy as part of their treatment and, of those, it was the first type of treatment for 49%.

### **Explanation of radiotherapy side effects**

Nearly two thirds (63%) of those who had radiotherapy said that the possible side effects were *definitely* explained to them (slightly fewer than for chemotherapy), while 26% said they were given this information *to some extent*, and 11% said side effects were *not* explained (rather more than for chemotherapy).

### **Control of radiotherapy side effects**

Nearly two-thirds (65%) of responders felt that hospital staff *did everything possible* to control the side effects of radiotherapy (fewer than for chemotherapy), while 25% felt this was true only *to some extent* and 10% felt staff could have done more to control the side effects of radiotherapy.

## **14 Hospital outpatients appointments**

### **Length and frequency of appointments**

Most patients (84%) thought that outpatients appointments to see a doctor were about the right length of time, but 12% thought they were *too short* and 4% said they were *too long*.

Patients tended to be less satisfied with the frequency of appointments: only 55% thought their appointments were *definitely* frequent enough.

*Not having to wait too long between hospital appointments [would be an improvement].*

*We had no continuity of treatment and everything took too long - doctors on holiday and nobody to step in. Wrong diagnosis. Long waits for appointments at critical stages.*

Some said there had been too long a delay before for tests had been carried out.

*We never had enough time for treatment because hospitals took 5 weeks before tests were done due to consultants being on holidays.*

Others had found it particularly difficult to have to wait a long time for test results, especially if the delay seemed unnecessary.

*The uncertainty of what was going on and waiting on results over public holidays, etc.*

## Being kept waiting

For some, the way they were treated when going for outpatients appointments could have been improved, especially the time they were kept waiting:

*When he went in when things had gone wrong he would be in for a full day waiting for doctors nurses medicine etc and that was a day wasted of his short life.*

*We have to be at the hospital for chemo 1.5 hours before treatment. Last time, we were kept waiting 3.5 hours, which is far too long for sick people to wait around.*

*Trying to keep to appointment times [would be an improvement].*

*Hospitals never seem to keep to the appointment time given to us. Waiting for an hour over appointment time is very distressing especially when you feel unwell.*

*On one occasion at [\*\*\*], we had to wait for 4 hours in a draughty corridor because the waiting room was full. Then we had to go to the other side of the hospital to the pharmacy with another long wait. Total time 6 hours with no food and only drinking water.*

## Urgent outpatients appointments

Sixty per cent of responders had tried to make urgent outpatients appointments. Of those, most had found it *very easy* (40%) or *fairly easy* (38%). However, 15% of those who tried found it *not very easy* and 7% found it *not at all easy* to make outpatients appointments.

## 15 Hospital inpatient care

### Overall standards of hospital care

Many patients commented on the high quality care they had received from their local hospital.

*I feel I have been very fortunate to have had the team of doctors, nurses and support staff I have had looking after me.*

*The hospital seemed to do anything it could to help me.*

*The care, information and personal empathy from the London specialists we are now with has been excellent. This includes the surgeon, oncologist and the specialist nurses.*

A few responders mentioned poor nursing care in hospital.

*General nursing care was poor and we stopped going to hospital with health problems because of this.*

*The attitude of the majority of nurses is poor. Most have an "attitude". Gone is compassion and care. Many nurses are now "nurse practitioners", interested only in clinical procedures. Patients are tolerated, relatives ignored.*

### Patients getting understandable answers to their questions

Just 56% of the responders said that doctors "always" gave understandable answers to their questions.

*I cannot fault the staff at [\*\*\*]. They are so caring and explain everything.*

*The care that has been received from the team at [\*\*\*] and the staff at the [\*\*\*] has been exceptional, friendly, caring and always make time to explain everything.*

*My late husband was under the care of a specialist who was very experienced and knowledgeable about mesothelioma who got to know him as a person and always gave him enough time to ask all his questions, regardless of how big or small her clinic was.*

*[My oncologist] has always answered my emails promptly and always been positive.*

*The medical team at the hospital who dealt with my mother initially were so kind and made us all totally at ease where we felt able to ask anything of them. Nothing was too much trouble. The consultant especially was fantastic.*

*I had the facility to email the oncologist, which I believed helped all round in terms of getting things done, and also communicating information to her quicker, rather than waiting for the clinical appointment.*

Others found it difficult to get answers to their questions:

*My oncologist was curt, she offered no guidance to me. The only option she gave was chemo and never explained the after effects of this treatment. I had to ask all the questions which she really didn't want to answer.*

### **Passing on information to patients**

Fifty-three per cent of the responders thought that doctors *always* gave them all the information they had about their mesothelioma and its treatment:

*When trying to find out about survival rate following chemotherapy, the best advice came from [name removed] she gave straightforward answers to our questions.*

However, 27% said they only gave them all the information *sometimes* and 20% said that doctors did *not* give them all the information they had.

*We always had to ask again and again how far the disease was progressing, especially after Mam went into a nursing home.*

*At no stage were we informed the prognosis was terminal and that death was imminent there was no time for the patient or family to prepare.*

*When asked a question, medical professionals should give honest answers and not be like MPs- answer yet say nothing.*

### **Hospital doctors' knowledge of mesothelioma**

Overall, 73% of responders said they thought *all* (49%) or most (24%) of the doctors treating them knew enough about how to treat mesothelioma, but 19% thought *only some* of them knew enough and 8% thought *none* of their doctors knew enough about treating mesothelioma.

Others commented on doctors' lack of knowledge of how to treat mesothelioma.

*Despite being on a specialist chest ward, patient's drain tube was not working for a week despite x-ray showing left lung was not visible. Young doctors seemed to think they didn't need to treat as hoped patient would be moved to specialist hospital if mesothelioma was confirmed after biopsy. But when suspected diagnosis was confirmed specialist hospital said too late for any treatment apart from pain control. Patient died 3 days later.*

*I've had to search to get any information about peritoneal Meso online no one, well any of my healthcare professionals, know anything at all about my type of cancer.*

*The Doctors did not know which way to turn or how to really treat the patient.*

*After having drainage operation [\*\*\*]. My husband was sent home with a DIY kit, with DVD instructions on how to change draining tubes etc. The nurses and his doctors had no idea how to do this.*

## **Being treated with respect**

Very few (4%) of responders said that hospital doctors or nurses *often* talked in front of them as if they were not there, and 15% said this happened *sometimes*.

*The attitude of doctors [could be improved], talking as if you aren't there and incapable of understanding them.*

*Professionals could be more considerate. It's been a constant battle getting them to listen, they don't tell you what's going on, or what's going to happen.*

*Doctors bedside manners [should be improved] and more caring nurses. Some nurses very rude and unsympathetic.*

*Educate local hospitals not to write off patients who have mesothelioma. They deserve respect and dignity and hope despite the poor prognosis of this disease.*

*No, in fact I was very disappointed at the way [\*\*\*] treated my husband in fact one doctor told him she didn't have time to speak to him she would be somewhere else. It seemed my husband was just dismissed out of hand.*

*He has been treated like a lab rat as far as these doctors as concerned.*

## **Being told different things by different professionals**

Forty per cent of responders said that they had been told different things about their mesothelioma by different nurses or doctors.

*Conflicting opinions from health professionals has left us completely and utterly confused as to what treatment we should be following.*

*I am concerned that the oncologist took only one course of action (no chemotherapy until showing signs of return) but the surgeon said I should have chemotherapy. Who should the patient listen to? We went along with the oncologist, as he was very persuasive but in hindsight, perhaps I should have insisted on the chemotherapy.*

## **Pain control in hospital**

Sixty-two per cent of responders felt that hospital doctors and nurses *always* did everything they could to control their **Pain**.

*The nursing team at [\*\* hospital] did everything they could in his last days, but their hands were tied because they could not give him access to adequate pain relief.*

*I was given painkillers as often as I wanted for pain relief.*

Others felt the hospital staff could have done more to control their pain:

*The thoracoscopy was a painful process for my husband - not enough 'local' was administered!*

*The pain was only controlled with paracetamol and codeine, and latterly small doses of oramorph just before he died. This inadequate pain relief therefore denied my dad the opportunity for any quality of life in his last days and deprived him of the opportunity for any end of life planning. He also died a horrendous agonising death because he was a tall, broad man and the drugs the nurses could offer him in his final hours had little effect.*

*I never felt pain control was adequately addressed. I also think Dad (the patient) wasn't asked enough probing questions, to elicit how bad he had really been, because he would tend to answer "fine, thank you", even when he had been beside himself with pain only the day before.*

However, only 49% thought they did everything to control **Breathlessness**, 32% for controlling **Fatigue**, and 30% thought they always did everything they could to control **Coughing**.

*A huge thank you for fitting the pleural drain which enabled my husband to live a comparatively normal life for the last few months.*

### **Information on leaving hospital**

On leaving hospital, 42% of patients said that they were *not* given clear written information about *what they should and should not do*, and 18% were *not* told who to contact if they were worried about their condition after they had gone home.

Only 34% of patients said that their family members were *definitely* given enough information to help them support them at home:

*The team at Guys hospital were generally very attentive and supportive. The patient/carer day we attended helped us to meet similar people and share stories with them.*

33% said their family members were *not* given this information to help support them at home:

*Possibly more advice for how the family can cope and care for the sufferer.*

## **16 Clinical Nurse Specialists**

The majority of responders (88%) said they were given the name of a Clinical Nurse Specialist (or Key Worker) who would be in charge of the care they received.

Experiences of Clinical Nurse Specialists were generally very positive. Many of the positive comments referred to these nurses:

*The Lung Specialist Nurse at the local hospital was always very willing to help and advise.*

*Having the support of a specialist nurse for mesothelioma was absolutely invaluable. She knew everything we needed to know and being able to contact her at any time and ask for her advice as the disease progressed meant that I felt confident to nurse my husband at home until he died, which was what he wanted.*

*The lung nurse holds a meeting every 6 weeks for those suffering with all types of lung cancer. At these meetings there is the opportunity to talk to the sufferers. There are guest speakers such as physiotherapists, Macmillan nurses, representations from the hospice etc. The lung nurse is always available to speak with me.*

*The cancer care nurse was brilliant. Within a half hour of diagnosis, she had forms for a blue badge, which she said she would fill in any questions we couldn't and a list of solicitors.*

*Support of clinical nurse specialist has been outstanding.*

*Two specialist nurses have been always there for us, even on weekends and holidays. Either by email, text or phone.*

*My specialist nurse, at [\*\* Hospital] [has been particularly good]. Her support on so many levels, throughout this difficult journey she has shared with me, is something I do not know what I would have done without. I refer to humanity and compassion above and beyond medicinal duties. Please keep employing people like her as our remaining moments are so precious.*

*Our lung cancer specialist nurse has been excellent, very understanding and always helpful.*

Of those who had been assigned to a Clinical Nurse Specialist, 64% found it *always easy* to contact them; 83% said that their Clinical Nurse Specialist *always* listened carefully to them and 77% said they *always* gave understandable answers to their questions.

*The lung cancer specialist nurses and the consultant at [\*\* Hospital] were easy to talk to, very understanding and available when we needed help.*

Other responders commented that they would have liked such support:

*Named support worker would have helped who knew how to access help if needed. Treatment was in Edinburgh we live in Fife not always clear who to contact.*

*We didn't have a Mesothelioma Specialist Nurse at the time in [\*\*\*] and so the Lung Cancer Specialist Nurse didn't have time to spare with such a big caseload. This hurt because many of the cancers she would have been dealing with were self induced and potentially curable whereas the Mesothelioma patients were sentenced to death through no fault of their own without any hope of a cure.*

## 17 Emotional support

Only 55% of responders said that they were offered support in dealing with the emotional side of cancer. Some of the comments highlighted shortcomings in emotional care.

*Devastating diagnosis only two months before death. No counselling, etc and my Mum left emotionally devastated and her family bewildered and not comprehending what was going on.*

*I was frequently asked if I was coping and feeling OK but my daughter, who was still living at home then, was completely ignored by health professionals. I feel that the burden of caring for a terminal cancer patient at home is too great.*

*More understanding what the patient and family are going through. At one point my husband was told to go home and accept his cancer. Imagine how that made all of us feel.*

## 18 Self-help and support groups

Of the responders who were interested in getting information about self-help groups, 71% said they were given information about them and 55% of the responders had had contact with an asbestos support group.

*The only good thing about having Mesothelioma is the help received from the self help group.*

*Support group is definitely the most positive thing to have, to see others in same situation, and how they are dealing with their situation so well.*

Many comments referred to the help responders had received from support groups.

*The **Mesothelioma UK** helpline nurses have been very informative and supportive.*

However, 29% said they did *not* get information about self-help groups, but would have liked it.

*There should be people available at the hospitals who can offer support and advice who have had experience in dealing with mesothelioma, someone who knows firsthand the trauma this disease brings.*

Others wished there was a support group in their area:

*There were no support groups, no written info, no anything except a doctor saying you do know there's nothing we can do for you?*

*It would have been a great help for my husband to have been able to talk to other people who had received the treatment, who had the same condition, or who was going through the same things.*

## 19 Support at home

### District nurses, home helps, etc.

Forty-six per cent of patients said they were *definitely* given enough support at home (such as district nurses, home helps or physiotherapists), but 30% said they received such support only *to some extent* and 24% said they did *not* receive this support.

*The home support nurses and GPs were very good.*

However, others felt the support they were given at home was inadequate.

*Clear guidelines on how to access support in the community. An elderly, terminally ill patient would not have a chance without support of family, I worry for those patients that do not have full time support at home, it is a complete minefield for anyone without any previous contact with "the system".*

*Swifter access to aids required at home. My father became disabled within a few weeks of diagnosis and we had to purchase seat pads, wheelchairs, shower chair etc as they could take weeks to come through via local authorities*

*The consultant and nurse said they would arrange certain types of support which have never materialised.*

*More help at home [is needed] if the patient decides that they want to die there. My Mum and myself were left caring for Dad 24 hrs a day on our own and only got help on the last day and a half.*

### Financial help and free prescriptions

Almost all responders (92%) got the information they needed about getting financial help.

*You are helped financially so you have no worries about the extra you are spending.*

*We were helped with completing forms for benefits as this is something we had never done but as it turned out really needed the financial help.*

Of those responders who needed information about getting free prescriptions, 83% were given this information, but 17% were not.

## 20 Planning end-of-life care

Of the responders who would have liked support to plan for end-of-life care, only 40% received such support.

*Planning care to end of life at home was excellent.*

*More information on end game [was needed].*

Several people commented that the speed at which the disease progressed had shocked them and, in some cases, the health professionals.

*[We would have liked] palliative care rather than palliative rush to death.*

*I felt that the speed of my husband's death took the community medical staff by surprise. I was able to cope and my husband died very peacefully at home but looking back I feel that we should have had some end of life discussion before that point with them and maybe a lack of experience of mesothelioma was the cause.*

*I think it should be explained how quickly the patient deteriorates and then you would be prepared for death!*

*I am a nurse but was still shocked at how mesothelioma progresses.*

## 21 Palliative care

Sixty-six per cent of responders said that they received care from a palliative care nurse (such as a Macmillan Nurse or Marie Curie nurse).

### Macmillan nurses

There were many positive comments about Macmillan Cancer Support nurses:

*Our Macmillan nurse was one in a million who helped all the family during and after my husband's illness.*

*Macmillan nurses who came to our home [were a very good thing about our care], as it made it possible to keep my husband at home with me till he died which was he wanted.*

*Macmillan key nurses have been fantastic in their sympathy and support.*

*Macmillan nurse was exceptional.*

*Would like to say how fantastic the support has been from the Macmillan nurses. They have been very caring, helpful and full of support for me and my family. Thank you to such a great team!*

*Whilst my partner was still being cared for by the hospital, the specialist Macmillan nurse was wonderful both with her practical and emotional support.*

*We have had the most care and help from the staff at Sue Ryder Care and from a Macmillan Nurse Care Worker. Without exception, they have always been of the utmost support and absolutely nothing has been too much trouble or beyond their 'job description'.*

*Dad couldn't praise his Macmillan nurse highly enough.*

*The only thing that was good about the care and treatment of mesothelioma was the support that the family received from our Macmillan nurse and office staff.*

However, several experiences of Macmillan nurses were negative:



*No help from Macmillan nurse who got in touch 6 months later.*

*Let down badly by Macmillan nurse will never support them. Yes the Macmillan nurse was so unhelpful disgusted had to report her to her boss!*

*Our Macmillan nurse is always almost impossible to contact.*

*Although a Macmillan Nurse was allocated to us she did nothing to help our plight except a few simple aids. She always came dressed in black head to foot and was like an angel of Death.*

*I would never like anyone to have a Macmillan nurse like we had she should have been struck off!*

*We were not given enough support from the Macmillan team. In fact they were not at all helpful. e.g. my husband's BP was very low and as a result was collapsing. The response was "we do not do blood pressure". I could not contact them easily--would leave messages that never got a response. Left feeling very lost and alone.*

*Macmillan Nurse didn't 'do' very much and seemed not to be the 'Angel' everyone describes.*

## **Other palliative care nursing charities**

Other charities, including Marie Curie were also mentioned in positive comments:

*The district nurse and Marie Curie were supportive at the very end of my husband's illness.*

*The care in the Marie Curie "Breathing Space" Day Therapy on a Friday [was a very good thing about our care].*

*I know the pain specialist nurse from [the hospice] gave Dad a new lease of life when she first came and made it so he was able to live life to the full for about 18 mths afterwards.*

*[The hospice] and Macmillan were always easy to contact, especially for immediate advice - even in the middle of the night.*

## **Hospice care**

Several respondents commented positively on the care they had received from a hospice.

*The treatment received from local doctor and local hospice was so caring and sensitive to my husband's needs. They helped him keep his dignity to the last.*

*The support from the hospice where my husband passed away [was very good]. They were there to support me for the year afterwards.*

*My husband had wonderful treatment and care but in the end none of it worked and he died in [the hospice], who were wonderful with their pain relief and care.*

*[\*\*Hospice] were wonderful with helping with the pain control and general care.*

*The local hospice at home were absolutely fantastic. Nothing was too much for these people. They took charge from day one and helped arrange all medications etc and the support they give was unbelievable to my dad and all our family.*

However, not all experiences of hospice care had been positive.

*The hospice that my Dad was admitted to at the end showed no compassion at all. My mother had no help caring for my father from any cancer support group.*

*Pain control towards end of life could not seem to be managed despite my husband being in the hospice for the last 3 weeks of his life, when the mesothelioma had spread to lymph nodes and he really was in agony despite the constant shots of morphine being administered by the hospice.*

*My father died in the local hospice, although the nurses were friendly, they were very busy and often made me feel that my dad wasn't important. He was put in a communal ward the same day as being told he had 2 weeks to live. My dad being a very private man was very distressed by this. I would like to see more help in hospices.*

## **22 Co-ordination of care**

Seventy-six per cent of responders said that the professionals providing their care *always* or *most of the time* worked well together to provide the best possible care.

*We were impressed, throughout my husband's illness, with the speed and efficiency which we moved from one element of his care to the next, starting with the G.P., and finishing at the chemist. Undoubtedly the expertise, experience, confidence and understanding of the Meso Nurse consultant had a huge part to play in this achievement.*

*It has been a source of constant reassurance to know that support and advice are available at the end of a phone almost any time and also to be aware of the extent to which the professionals involved cooperate and communicate with each other.*

However, others felt that communications between healthcare professionals or organisations could have been better:

*Co-ordination between various groups involved in care [would improve my care]. I am visiting 3 hospitals - one for blood tests/scans/chemo, another one for consultant and another in London (my choice for 2nd opinion) but it is a case of right hand not knowing what left hand is doing.*

*Better communication between hospitals [would improve my care] - We had difficulty getting scan results from [\*\*\*] to [\*\*\*].*

*More liaisons needed between departments giving different treatments. Had experience of one department not know what other done or doing.*

*There were lapses in communication between different departments and different hospitals. The Macmillan nurse at the main hospital did keep things together but even so there were gaps.*

*The patient was discharged rather quickly to a secondary hospital, which caused great distress. There was no information at this time regarding her care and secondary hospital discharged patient rapidly also.*

## **Uncertainty about where to go for help**

Several responders commented that they did not know where to go for help and some felt there was a general reluctance for anyone to take responsibility for their care.

*It is not clear who my first port of call is. I feel they are waiting for me to die before anyone takes any responsibility.*

*Having received information from a Consultant Oncologist, the route for further face to face information if it should be required is not clear. GPs are not really in the loop. Does one direct try to have another Consultant appointment? If so, how? Direct contact with the Consultant?*

*No one seems to choose or feel it is their job to deal with this particular disease in any way positively outside the Macmillan or Sue Ryder organisations.*

*Once chemotherapy was stopped it was hard to know who to contact when needing help and even more so out of hours and at weekends.*

*Could have been more visits or even regular phone calls just to say 'how are you coping'. Especially the patient and secondly the carer. Would have meant a lot. From discharge from hospital, seen twice by doctors and nurses, then no visits or enquiries for 1 month to date.*

And one responder did not find it easy to contact the nursing team out of hours.

*Contacting the Nursing Team was a problem between 6-8am and between 5:30-7pm, as this is the change over time! Unable to get hold of anyone!*

### **The role of the multi-disciplinary team (MDT)**

Most patients (62%) said that someone had explained to them that a multi-disciplinary team had reviewed their case, but 38% were not told this. Only 49% of all responders said that the role of the MDT had been explained to them, but 83% of those who had been told an MDT had reviewed their case also said that its role had been explained to them.

*No good having MDT if they cannot agree. Patient should be party to the report. Communication poor across people involved; too much repetition. Approach is too general; not personalised.*

### **Did hospital doctors give GPs the right information about mesothelioma?**

Sixty-one per cent of responders thought the hospital doctor *definitely* gave the GP enough information about the patient's mesothelioma, but 23% thought this was only true *to some extent* and 16% thought hospital doctors could have done more to provide their GP with the right information.

*The only weak link in the chain of professionals has been the GP who didn't seem to have much knowledge of this cancer.*

## **23 GPs and community nurses**

Fifty-five per cent said they *definitely* received good support from their GP and community nurses, and many of the positive comments reflect these views:

*Our GP couldn't have been better.*

*Our doctor could not have given us better support in the final weeks.*

*My GP has been excellent throughout this journey into the unknown.*

*Our GP was very kind and came when called, he done all he could.*

*The district nurses were excellent both in the care the patient but also were lovely to the family.*

Two responders were particularly grateful that their GPs had made an effort to find out more about Mesothelioma following their diagnosis:

*Our GP did not seem to know much about Meso when Dad was first diagnosed, but we think he must have made it his duty to find out, and the next time Dad saw him he knew all about it. He would pop in especially in the last couple of months and see how Dad was, saying 'I was passing, so thought I would see how you are.'*

*Local GP did not know about the disease but he made sure he found out and was a great support to us. Also the district nurses.*

However, 26% said the support they received from their GP was good only to some extent, and 19% felt that their GP and community nurses could have done more to support them.

*The service from the district nursing team could have been improved. Irregular visits from nurses really upset my father.*

*The district nurse was not at all supportive of the family. We were receiving, if we were lucky, a weekly visit until we pushed for extra. We had to ask to be put in contact with Marie Curie. As we were caring for my mum at home, we were given support by Marie Curie in the last week of my mother's life and they were shocked at the lack of support we had had prior.*

*The care provided by our GP was poor. We never received a visit. Ordering meds was hard.*

## 24 Legal matters

### Making a claim

Fifty-three per cent of the responders were given a list of lawyer firms who specialise in claims for mesothelioma, and a further 23% were put in contact with lawyers through an asbestos support group.

*All solicitors have been a wonderful support.*

One person said that they did not want to discuss legal matters when they were first diagnosed.

*I understand that it is important, and that the sooner you claim the better, but I felt that the emphasis on the monetary compensation we could claim sat very badly with the stunning nature of the diagnosis. As did the information on the legal position. We had all this at the same time as the diagnosis and it was all too much. It might have been better to have spread this over 2 meetings.*

### The role of the coroner

Forty-one per cent of responders said they had been told about the role of the Coroner in mesothelioma. Some responders commented on negative experiences of the Coroner's involvement.

*The family was never informed about what would happen when Dad did die. He died at home. We did not know the police would be there and statements taken. We did not know there would be an inquest. We did not know we would have to wait for the body to be released by the coroner before we could arrange the funeral.*

*The GP didn't know exactly what to do or who to contact immediately after death, hospital mortuary were appalling and made us travel to identify the person who had died even though they had died at home in our presence. Coroner's Office didn't keep family informed and were unhelpful every time we had to chase them for information.*

## 25 More funding for research

Many of the comments about what could be improved referred to a wish for more research to find better treatments or a cure for mesothelioma.

*It would be fantastic if further research into the efficacy of the chemoembolisation could be undertaken and therefore for a clinical trial to be started in this country. The effects appear to be useful in the treatment of this aggressive and very painful cancer and it does not have so many side-effects.*

*Continued targeted research exploring why mesothelioma is triggered in some and not others [is needed].*

*There have only been 12 trials in this country compared to thousands and thousands for breast cancer, lung cancer etc.*

*It is really so outrageous that the government does not fund research into this dreadful disease.*

*There should be greater resources dedicated to research into treatment of mesothelioma and this should be funded by the government as well as public charitable sources. This is because there has not been research into treatment of this disease in the past and it should be addressed.*

## Acknowledgements

Mesothelioma UK would like to thank patients and carers for completing the survey; National Lung Cancer Forum for Nurses members (NLCFN), Mesothelioma Nurse Action Team (M-NAT) and British Thoracic Oncology Group (BTOG) and Asbestos Support Groups for helping to publicise this survey; Patient Perspective for carrying out the survey; and Mick Knighton Mesothelioma Research Fund for contributing to the cost of commissioning the survey.

## Contact Details for Mesothelioma UK



### **Mesothelioma UK - National Macmillan Mesothelioma Resource Centre**

University Hospitals of Leicester NHS Trust  
Glenfield Hospital  
Grobby Road  
Leicester  
LE3 9QP

Helpline 📞 0800 169 2409  
Fax 0116 250 2810  
Email [mesothelioma.uk@uhl-tr.nhs.uk](mailto:mesothelioma.uk@uhl-tr.nhs.uk)  
Website [www.mesothelioma.uk.com](http://www.mesothelioma.uk.com)

## Appendix – Full tables of survey responses

### Q1 Who is completing the survey?

		Frequency	Valid Percent
Valid	1 The person with mesothelioma	272	42.3
	2 The carer/ partner/ relative of the person with mesothelioma	153	23.8
	3 The bereaved carer/ partner/ relative of the person with mesothelioma	218	33.9
	Total	643	100.0
Other	No response	9	
Total		652	

### Q2 Were you helped to identify where asbestos exposure may have occurred?

		Frequency	Valid Percent
Valid	1 No, not helped	100	16.9
	2 Already knew	260	43.8
	3 Yes, by a doctor/nurse	76	12.8
	4 Yes, by asbestos support group	64	10.8
	5 Yes, by someone else	93	15.7
	Total	593	100.0
Other	No response	59	
Total		652	

### Q3 Prior to the mesothelioma diagnosis, were any other asbestos related diseases diagnosed?

		Frequency	Valid Percent
Valid	1 Yes, Pleural Plaques	46	7.5
	2 Yes, Pleural Thickening	34	5.5
	3 Yes, Asbestosis	7	1.1
	4 No	499	81.3
	5 Don't know	28	4.6
	Total	614	100.0
Other	No response	38	
Total		652	



**Q4 Prior to the mesothelioma diagnosis, was the possibility of mesothelioma or another asbestos related disease a worry?**

		Frequency	Valid Percent
Valid	1 Yes, always	74	12.0
	2 Yes, recently	47	7.6
	3 No	497	80.4
	Total	618	100.0
Other	No response	34	
Total		652	

**Q5 Before being told a hospital appointment would be required, how many GP appointments had there been for the health problems caused by mesothelioma?**

		Frequency	Valid Percent
Valid	1 None, the GP was not seen before going to hospital	60	10.2
	2 1-2 GP appointments	298	50.6
	3 3 or 4 GP appointments	120	20.4
	4 5 or more GP appointments	111	18.8
	Total	589	100.0
Other	5 Don't know	23	
	No response	40	
	Total	63	
Total		652	

**Q6 Were all of the tests carried out at the local hospital?**

		Frequency	Valid Percent
Valid	1 Yes	389	64.0
	2 No	219	36.0
	Total	608	100.0
Other	No response	44	
Total		652	

**Q7 How far away were the tests carried out?**

		Frequency	Valid Percent
Valid	1 0-10 miles	47	20.3
	2 11-25 miles	88	37.9
	3 26-50 miles	63	27.2
	4 50+ miles	34	14.7
	Total	232	100.0
Other	No response	420	
Total		652	

**Q8 Did you mind having to travel for the tests?**

		Frequency	Valid Percent
Valid	1 Yes	32	13.6
	2 No	203	86.4
	Total	235	100.0
Other	No response	417	
Total		652	

**Q9 Which of these tests were carried out before the diagnosis of mesothelioma?**

Test	Frequency	Percent
CT Scan	430	66.0
PET Scan	32	4.9
MRI Scan	115	17.6
Bronchoscopy	78	12.0
Laparoscopy	19	2.9
Sample of the fluid from lung drained for tests	390	59.8
Sample of the fluid from abdomen drained for tests	22	3.4
Needle biopsy whilst being scanned (CT or ultrasound)	149	22.9
Thoracoscopy with local anaesthetic (awake)	74	11.3
Thoracoscopy with general anaesthetic (asleep)	102	15.6
Surgical biopsy with general anaesthetic	223	34.2
Don't know	22	3.4
Another test	43	6.6

**Q10 How many times was fluid drained?**

		Frequency	Valid Percent
Valid	1 0 times / never	92	15.7
	2 1 time	221	37.7
	3 2-4 times	219	37.4
	4 5 or more times	54	9.2
	Total	586	100.0
Other	No response	66	
Total		652	

**Q11 Before the tests, was information provided about the tests?**

		Frequency	Valid Percent
Valid	1 Yes, definitely	270	48.7
	2 Yes, to some extent	211	38.1
	3 No	73	13.2
	Total	554	100.0
Other	4 Don't know/Can't remember	35	
	No response	63	
	Total	98	
Total	652		

**Q12 Was the information provided about the tests easy to understand?**

		Frequency	Valid Percent
Valid	1 Yes, definitely	249	46.9
	2 Yes, to some extent	235	44.3
	3 No	47	8.9
	Total	531	100.0
Other	4 Don't know/Can't remember	51	
	No response	70	
	Total	121	
Total	652		

**Q13 Who was it that first told you about the mesothelioma diagnosis?**

		Frequency	Valid Percent
Valid	1 A hospital doctor	506	86.5
	2 A hospital nurse	20	3.4
	3 A GP (family doctor)	17	2.9
	4 A friend or relative	10	1.7
	5 Nobody – I/we worked it out ourselves	10	1.7
	6 Someone else	22	3.8
	Total	585	100.0
Other	No response	67	
Total	652		

**Q14 Was the explanation of the mesothelioma diagnosis given in an understandable way?**

		Frequency	Valid Percent
Valid	1 Yes, completely	325	55.4
	2 Yes, to some extent	213	36.3
	3 No	49	8.3
	Total	587	100.0
Other	4 Don't know/Can't remember	8	
	No response	57	
	Total	65	
Total		652	

**Q15 Was the explanation given in a sensitive way?**

		Frequency	Valid Percent
Valid	1 Yes	380	65.7
	2 It could have been done a bit more sensitively	107	18.5
	3 It could have been done a lot more sensitively	91	15.7
	Total	578	100.0
Other	4 Don't know/Can't remember	18	
	No response	56	
	Total	74	
Total		652	

**Q16 When the diagnosis of mesothelioma was made, was written information about that type of cancer provided?**

		Frequency	Valid Percent
Valid	1 Yes	372	66.8
	2 No	167	30.0
	3 Did not need written information	18	3.2
	Total	557	100.0
Other	4 Don't know/Can't remember	35	
	No response	60	
	Total	95	
Total		652	

**Q17 Was the written information provided at the time of diagnosis easy to understand?**

		Frequency	Valid Percent
Valid	1 Yes, very easy	174	40.9
	2 Yes, fairly easy	202	47.5
	3 No, not very easy	33	7.8
	4 No, not at all easy	16	3.8
	Total	425	100.0
Other	No response	227	
Total		652	

**Q18 Did someone explain that a multidisciplinary team (MDT) had reviewed this case?**

		Frequency	Valid Percent
Valid	1 Yes	291	62.2
	2 No	177	37.8
	Total	468	100.0
Other	3 Don't know	116	
	No response	68	
	Total	184	
Total		652	

**Q19 Did someone explain the role of the multidisciplinary team (MDT)?**

		Frequency	Valid Percent
Valid	1 Yes	261	48.4
	2 No	278	51.6
	Total	539	100.0
Other	No response	113	
Total		652	

**Q20 Was written information provided about treatment and side effects of treatment?**

		Frequency	Valid Percent
Valid	1 Yes and it was easy to understand	332	61.8
	2 Yes but it was difficult to understand	57	10.6
	3 No, not given written information	148	27.6
	Total	537	100.0
Other	4 Don't know/Can't remember	42	
	No response	73	
	Total	115	
Total		652	

**Q21 Were you involved as much as you wanted to be in decisions about which treatment(s) to have?**

		Frequency	Valid Percent
Valid	1 Yes definitely	316	63.5
	2 Yes to some extent	131	26.3
	3 No, but would have liked to be more involved	51	10.2
	Total	498	100.0
Other	4 Only one type of treatment was suitable	55	
	5 Don't know/Can't remember	13	
	No response	86	
	Total	154	
Total		652	

**Q22 Was information about participating in a clinical trial provided?**

		Frequency	Valid Percent
Valid	1 Yes	179	33.9
	2 No	349	66.1
	Total	528	100.0
Other	3 Don't know	47	
	No response	77	
	Total	124	
Total		652	

**Q23 Was surgery carried out as part of the treatment for Mesothelioma?**

		Frequency	Valid Percent
Valid	1 Yes	207	36.1
	2 No	367	63.9
	Total	574	100.0
Other	No response	78	
Total		652	

**Q24 Was surgery the first, second or third type of treatment for Mesothelioma?**

		Frequency	Valid Percent
Valid	1 First	163	82.7
	2 Second	26	13.2
	3 Third	8	4.1
	Total	197	100.0
Other	No response	455	
Total		652	

**Q25 Did a member of staff explain what would be done during the operation?**

		Frequency	Valid Percent
Valid	1 Yes completely	157	76.6
	2 Yes to some extent	43	21.0
	3 No, would have liked an explanation	5	2.4
	Total	205	100.0
Other	4 Don't know/Can't remember	2	
	No response	445	
	Total	447	
Total	652		

**Q26 Beforehand, was written information about the operation provided?**

		Frequency	Valid Percent
Valid	1 Yes and it was easy to understand	100	58.1
	2 Yes but it was difficult to understand	14	8.1
	3 No, not given written information	58	33.7
	Total	172	100.0
Other	4 Did not need written information	13	
	5 Don't know/Can't remember	22	
	No response	445	
	Total	480	
Total	652		

**Q27 After the operation did a member of staff explain how it had gone in an understandable way?**

		Frequency	Valid Percent
Valid	1 Yes, completely	103	51.2
	2 Yes, to some extent	75	37.3
	3 No, would have liked an explanation	23	11.4
	Total	201	100.0
Other	4 Did not need an explanation	3	
	5 Don't know/Can't remember	2	
	No response	446	
	Total	451	
Total	652		

**Q28 Was chemotherapy carried out as part of the treatment for Mesothelioma?**

		Frequency	Valid Percent
Valid	1 Yes	359	62.7
	2 No	214	37.3
	Total	573	100.0
Other	No response	79	
Total		652	

**Q29 Was chemotherapy the first, second or third type of treatment for Mesothelioma?**

		Frequency	Valid Percent
Valid	1 First	213	60.7
	2 Second	100	28.5
	3 Third	38	10.8
	Total	351	100.0
Other	No response	301	
Total		652	

**Q30 Were the possible side effects of chemotherapy explained in an understandable way?**

		Frequency	Valid Percent
Valid	1 Yes, definitely	247	69.8
	2 Yes, to some extent	99	28.0
	3 No, side effects were not explained	8	2.3
	Total	354	100.0
Other	4 Did not need an explanation	2	
	5 Don't know/Can't remember	2	
	No response	294	
	Total	298	
Total		652	

**Q31 Did the hospital staff do everything possible to control the side effects of chemotherapy?**

		Frequency	Valid Percent
Valid	1 Yes, definitely	258	74.8
	2 Yes, to some extent	65	18.8
	3 No, they could have done more	22	6.4
	Total	345	100.0
Other	4 Did not have any side effects from chemotherapy	3	
	No response	304	
	Total	307	
Total		652	



**Q32 Was radiotherapy carried out as part of the treatment for Mesothelioma?**

		Frequency	Valid Percent
Valid	1 Yes	242	43.4
	2 No	316	56.6
	Total	558	100.0
Other	No response	94	
Total		652	

**Q33 Was radiotherapy the first, second or third type of treatment for Mesothelioma?**

		Frequency	Valid Percent
Valid	1 First	113	48.7
	2 Second	80	34.5
	3 Third	39	16.8
	Total	232	100.0
Other	No response	420	
Total		652	

**Q34 Were the possible side effects of radiotherapy explained in an understandable way?**

		Frequency	Valid Percent
Valid	1 Yes, definitely	144	63.2
	2 Yes, to some extent	59	25.9
	3 No, side effects were not explained	25	11.0
	Total	228	100.0
Other	4 Did not need an explanation	4	
	5 Don't know/Can't remember	6	
	No response	414	
Total		424	
Total		652	

**Q35 Did the hospital staff do everything possible to control the side effects of radiotherapy?**

		Frequency	Valid Percent
Valid	1 Yes, definitely	131	65.5
	2 Yes, to some extent	49	24.5
	3 No, they could have done more	20	10.0
	Total	200	100.0
Other	4 Did not have any side effects from radiotherapy	31	
	No response	421	
	Total	452	
Total		652	

**Q36 Generally were the appointments with the doctor at outpatients too short, about right, or too long?**

		Frequency	Valid Percent
Valid	1 Too short	67	12.0
	2 About right	470	84.2
	3 Too long	21	3.8
	Total	558	100.0
Other	No response	94	
Total		652	

**Q37 Were the outpatients appointments with the doctor frequent enough?**

		Frequency	Valid Percent
Valid	1 Yes, definitely	297	54.7
	2 Yes, to some extent	166	30.6
	3 No	80	14.7
	Total	543	100.0
Other	4 Don't know/Can't remember	16	
	No response	93	
	Total	109	
Total		652	

**Q38 If you needed to arrange an urgent outpatient appointment with a doctor, how easy was it to do so?**

		Frequency	Valid Percent
Valid	1 Very easy	157	40.1
	2 Fairly easy	149	38.0
	3 Not very easy	60	15.3
	4 Not at all easy	26	6.6
	Total	392	100.0
Other	5 I never needed an urgent appointment	151	
	6 Don't know/Can't remember	17	
	No response	92	
	Total	260	
Total		652	

**Q39 As far as you know did the hospital/hospital doctor give the GP enough information about the mesothelioma**

		Frequency	Valid Percent
Valid	1 Yes, definitely	295	61.1
	2 Yes, to some extent	109	22.6
	3 No, they could have done more	79	16.4
	Total	483	100.0
Other	4 Don't know/Can't remember	95	
	No response	74	
	Total	169	
Total		652	

**Q40 Was good support received from the GP and practice nurses in relation to this mesothelioma diagnosis?**

		Frequency	Valid Percent
Valid	1 Yes, definitely	300	54.9
	2 Yes, to some extent	144	26.4
	3 No, they could have done more	102	18.7
	Total	546	100.0
Other	4 Don't know/Can't remember	25	
	No response	81	
	Total	106	
Total		652	

**Q41 Was the name of a Clinical Nurse Specialist or Keyworker provided, who would be in charge of the care delivered?**

		Frequency	Valid Percent
Valid	1 Yes	465	88.2
	2 No	62	11.8
	Total	527	100.0
Other	3 Don't know/Can't remember	36	
	No response	89	
	Total	125	
Total		652	

**Q42 How easy is it to contact the Clinical Nurse Specialist or Keyworker?**

		Frequency	Valid Percent
Valid	1 Always easy	304	63.6
	2 Sometimes easy and sometimes difficult	145	30.3
	3 Always difficult	29	6.1
	Total	478	100.0
Other	4 Have not tried to contact him/her	69	
	No response	105	
	Total	174	
Total		652	

**Q43 Does the Clinical Nurse Specialist or Keyworker listen carefully?**

		Frequency	Valid Percent
Valid	1 Yes, always	422	82.6
	2 Yes, sometimes	55	10.8
	3 No	34	6.7
	Total	511	100.0
Other	No response	141	
Total		652	

**Q44 Does the Clinical Nurse Specialist or Keyworker answer important questions in an understandable way?**

		Frequency	Valid Percent
Valid	1 Yes, always	377	77.4
	2 Yes, sometimes	88	18.1
	3 No	22	4.5
	Total	487	100.0
Other	4 I/we do not ask any questions	22	
	No response	143	
	Total	165	
Total		652	

**Q45 Were you given information about self-help groups for people with mesothelioma?**

		Frequency	Valid Percent
Valid	1 Yes	350	71.4
	2 No, would have liked this information	140	28.6
	Total	490	100.0
Other	3 It was not necessary	48	
	4 Don't know/Can't remember	20	
	No response	94	
	Total	162	
Total		652	

**Q46 Were you given information about how to get financial help or benefits?**

		Frequency	Valid Percent
Valid	1 Yes	497	91.7
	2 No, would have liked this information	45	8.3
	Total	542	100.0
Other	3 It was not necessary	23	
	4 Don't know/Can't remember	4	
	No response	83	
	Total	110	
Total		652	

**Q47 Were you offered any support in managing the emotional side of dealing with cancer?**

		Frequency	Valid Percent
Valid	1 Yes, was offered support	312	55.5
	2 Yes, would have liked more support	77	13.7
	3 No, was not offered any support	173	30.8
	Total	562	100.0
Other	No response	90	
Total		652	

**Q48 Were you given information about free prescriptions?**

		Frequency	Valid Percent
Valid	1 Yes	209	83.3
	2 No, would have liked this information	42	16.7
	Total	251	100.0
Other	3 It was not necessary	287	
	4 Don't know/Can't remember	24	
	No response	90	
	Total	401	
Total		652	

**Q49 Have you had contact with an asbestos support group?**

		Frequency	Valid Percent
Valid	1 Yes, in person	313	55.3
	2 Yes, by telephone only	34	6.0
	3 No	219	38.7
	Total	566	100.0
Other	No response	86	
Total		652	

**Q50 Were you advised about how to contact a lawyer who specialises in claims for mesothelioma?**

		Frequency	Valid Percent
Valid	1 Yes given a list of firms	301	53.4
	2 Yes given a lawyer's card	48	8.5
	3 Referred to an asbestos support group who put in contact with a lawyer	132	23.4
	4 No	83	14.7
	Total	564	100.0
Other	No response	88	
Total		652	

**Q51 Were you informed about the role of the coroner in Mesothelioma?**

		Frequency	Valid Percent
Valid	1 Yes	227	41.1
	2 No	325	58.9
	Total	552	100.0
Other	No response	100	
Total		652	

**Q52 Did hospital doctors answer important questions in an understandable way?**

		Frequency	Valid Percent
Valid	1 Yes, always	310	56.2
	2 Yes, sometimes	202	36.6
	3 No	40	7.2
	Total	552	100.0
Other	4 I/we do not ask any questions	7	
	No response	93	
	Total	100	
Total		652	

**Q53 Do you think the doctors treating the mesothelioma knew enough about how to treat the condition?**

		Frequency	Valid
--	--	-----------	-------

		Percent
Valid	1 Yes, all of them knew enough	265 49.1
	2 Most of them knew enough	128 23.7
	3 Only some of them knew enough	103 19.1
	4 None of them knew enough	44 8.1
	Total	540 100.0
Other	5 Don't know/Can't remember	17
	No response	95
	Total	112
Total		652

**Q54 Did hospital doctors or nurses talk in front of you as if you weren't there?**

		Frequency	Valid Percent
Valid	1 Yes, often	23	4.2
	2 Yes, sometimes	80	14.8
	3 No	439	81.0
	Total	542	100.0
Other	4 Don't know/Can't remember	21	
	No response	89	
	Total	110	
Total		652	

**Q55 Do you think that hospital doctors gave you all the information they had about the mesothelioma and treatment?**

		Frequency	Valid Percent
Valid	1 Yes, always	293	52.6
	2 Yes, sometimes	153	27.5
	3 No	111	19.9
	Total	557	100.0
Other	No response	95	
Total		652	

**Q56 Did it ever happen that one doctor or nurse said something about mesothelioma or the treatment and another said something different?**

		Frequency	Valid Percent
Valid	1 Often	46	8.4
	2 Sometimes	127	23.1
	3 Only once	47	8.6
	4 Never	329	59.9
	Total	549	100.0
Other	No response	103	
Total		652	

**Q57 Did hospital doctors or nurses do everything they could to help control any breathlessness?**

		Frequency	Valid Percent
Valid	1 Yes, all of the time	206	49.2
	2 Yes, some of the time	149	35.6
	3 No, not at all	64	15.3
	Total	419	100.0
Other	4 No breathlessness	132	
	No response	101	
	Total	233	
Total		652	

**Q58 Did hospital doctors or nurses do everything they could to help control any fatigue?**

		Frequency	Valid Percent
Valid	1 Yes, all of the time	140	32.3
	2 Yes, some of the time	147	33.9
	3 No, not at all	147	33.9
	Total	434	100.0
Other	4 No fatigue	109	
	No response	109	
	Total	218	
Total		652	



**Q59 Did hospital doctors or nurses do everything they could to help control any coughing?**

		Frequency	Valid Percent
Valid	1 Yes, all of the time	86	29.7
	2 Yes, some of the time	126	43.4
	3 No, not at all	78	26.9
	Total	290	100.0
Other	4 No coughing	246	
	No response	116	
	Total	362	
Total		652	

**Q60 Did hospital doctors or nurses do everything they could to help control any pain?**

		Frequency	Valid Percent
Valid	1 Yes, all of the time	270	62.5
	2 Yes, some of the time	137	31.7
	3 No, not at all	25	5.8
	Total	432	100.0
Other	4 No pain	115	
	No response	105	
	Total	220	
Total		652	

**Q61 Was clear written information given about what the mesothelioma patient should or should not do after leaving hospital?**

		Frequency	Valid Percent
Valid	1 Yes	269	58.1
	2 No	194	41.9
	Total	463	100.0
Other	3 Can't remember	75	
	No response	114	
	Total	189	
Total		652	

**Q62 Did doctors or nurses say who to contact if worried about the condition or treatment after leaving hospital?**

		Frequency	Valid Percent
Valid	1 Yes	418	82.3
	2 No	90	17.7
	Total	508	100.0
Other	3 Can't remember	25	
	No response	119	
	Total	144	
Total		652	

**Q63 Did doctors and nurses give the family of the person with mesothelioma all the information needed to help them care for the person with mesothelioma at home?**

		Frequency	Valid Percent
Valid	1 Yes, definitely	172	34.5
	2 Yes, to some extent	162	32.5
	3 No	165	33.1
	Total	499	100.0
Other	4 No family or friends were involved	14	
	5 Family or friends did not want or need information	16	
	6 The person with mesothelioma did not want their family or friends to be given information	7	
	No response	116	
	Total	153	
Total		652	

**Q64 Was enough support provided at home (For example, district nurses, home helps or physiotherapists)?**

		Frequency	Valid Percent
Valid	1 Yes, definitely	179	45.9
	2 Yes, to some extent	118	30.3
	3 No	93	23.8
	Total	390	100.0
Other	4 Help was not needed	141	
	5 Don't know/Can't remember	4	
	No response	117	
	Total	262	
Total		652	

**Q65 Was support received in relation to planning care towards the end of life?**

		Frequency	Valid Percent
Valid	1 Yes	153	39.8
	2 No	231	60.2
	Total	384	100.0
Other	3 Didn't want to discuss it	94	
	4 Don't know/Can't remember	31	
	No response	143	
	Total	268	
Total		652	

**Q66 Was support received from a community palliative care nurse, for example a Macmillan nurse, Marie Curie nurse?**

		Frequency	Valid Percent
Valid	1 Yes	338	65.9
	2 No	175	34.1
	Total	513	100.0
Other	No response	139	
Total		652	

**Q67 Where did the care of the mesothelioma patient take place?**

		Frequency	Valid Percent
Valid	1 At an NHS hospital	488	91.7
	2 At a private hospital	15	2.8
	3 Both NHS and private hospitals	29	5.5
	Total	532	100.0
Other	No response	120	
Total		652	

**Q68 Overall have all the professionals involved worked well together to provide the best possible care?**

		Frequency	Valid Percent
Valid	1 Yes, always	255	46.9
	2 Yes, most of the time	161	29.6
	3 Yes, some of the time	99	18.2
	4 No, never	29	5.3
	Total	544	100.0
Other	5 Don't know/Can't remember	5	
	No response	103	
	Total	108	
Total		652	

**Q69 Overall how much information was received about the mesothelioma and its treatment?**

		Frequency	Valid Percent
Valid	1 Too much	16	2.9
	2 The right amount	369	67.1
	3 Not enough	165	30.0
	Total	550	100.0
Other	No response	102	
Total		652	

**Q70 Were you given information about obtaining a 2nd opinion about mesothelioma or its treatment?**

		Frequency	Valid Percent
Valid	1 Yes	70	16.2
	2 No	362	83.8
	Total	432	100.0
Other	3 It was not necessary	119	
	No response	101	
Total	Total	220	
Total		652	

**Q71 What was the age of the mesothelioma patient at diagnosis?**

		Frequency	Valid Percent
Valid	2 26-35	2	.4
	3 36-50	28	5.0
	4 51-65	197	35.3
	5 66-75	228	40.9
	6 76-85	95	17.0
	7 86	8	1.4
	Total	558	100.0
Other	No response	94	
Total		652	

**Q72 How long ago was Mesothelioma diagnosed?**

		Frequency	Valid Percent
Valid	1 In the last 6 months	160	29.0
	2 In the last 6 to 12 months	108	19.6
	3 More than 1 year ago	101	18.3
	4 More than 2 years ago	78	14.1
	5 More than 3 years ago	105	19.0
	Total	552	100.0
Other	No response	100	
Total		652	

**Q73 What type of Mesothelioma was diagnosed?**

		Frequency	Valid Percent
Valid	1 Pleural (chest)	524	96.0
	2 Peritoneal (abdomen)	22	4.0
	Total	546	100.0
Other	No response	106	
Total		652	

**Q74 Gender of the patient?**

		Frequency	Valid Percent
Valid	1 Male	445	80.3
	2 Female	109	19.7
	Total	554	100.0
Other	No response	98	
Total		652	

**Q75 Which region does the patient live in?**

		Frequency	Valid Percent
Valid	1 North East England	68	12.3
	2 North West England	62	11.2
	3 Midlands	114	20.7
	4 South East England	172	31.2
	5 South West England	55	10.0
	6 Scotland	58	10.5
	7 Wales	19	3.4
	8 Northern Ireland	4	.7
	Total	552	100.0
Other	No response	100	
Total		652	