

MAGS: The Healthcare Staff Mesothelioma Asbestos Guidance Study

Health carers with mesothelioma and their experiences
of presentation, treatment and care.



This report was inspired by Dr Mags Portman (pictured above) and is dedicated to her memory.

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Introduction



This project, the Healthcare Staff Mesothelioma Asbestos Guidance Study, takes the acronym MAGS. The name is inspired by Dr Mags Portman, a pioneering doctor in the treatment of

HIV. She championed the use of a new, effective treatment for HIV and enabled many to get that treatment in the UK who would not otherwise have done so. She was a popular, hardworking and inspirational figure. In January 2017 she was diagnosed with pleural mesothelioma¹. She commenced writing a blog that described her thoughts and experiences with the disease²; she also promoted research into mesothelioma³. In 2019, she died of mesothelioma at the age of 44.

Her death followed that of two other senior and equally respected physicians who also published remarkable insights into their experience. Dr Kieran Sweeney was an honorary professor of general practice who had published extensively. He died of mesothelioma in 2009 having written about his experiences and presented a YouTube broadcast⁴⁻⁶. Dr Andrew Lawson was a consultant in pain medicine who was diagnosed with mesothelioma in 2007 at the age of 48^{7,8}. Although told he was likely to survive no more than 12 months, he lived a further seven years; he and his wife speculate that this was through his use of experimental and trial treatments⁹.

These three doctors provided understanding of the experience of diagnosis and treatment for mesothelioma from the viewpoint of healthcare staff. Not all of this was positive, as we shall see later. In part as a result of this, the MAGS project was developed. The Mesothelioma UK team of clinical nurse specialists (CNS) has also been concerned about the number of healthcare staff they have cared for. Having a national CNS team, based throughout the country in NHS hospitals, provides a broad view of the impact of mesothelioma in certain patient cohorts that was not previously identified.

The aim of this study was to develop a critical account of the experiences of presentation, diagnosis, treatment and care for healthcare staff with mesothelioma. The objectives of the study were:

- i) To gather up up-to-date figures on the level of mesothelioma amongst healthcare staff.
- ii) To perform a rapid review of published research, examining the experience of healthcare staff who have developed mesothelioma;
- iii) To conduct some stakeholder consultation to inform the empirical study;
- iv) To collect and analyse data from healthcare staff who have developed mesothelioma;
- v) To develop recommendations for increasing awareness of the risk to healthcare staff, for example through information-giving as part of mandatory training.

The project was funded by Mesothelioma UK. As such, it formed part of some of the broader core aims of that charity, particularly, i) raising awareness of the dangers of asbestos and ii) mesothelioma prevention. This was highlighted by stakeholders (and also interviewees) who spoke of a desire 'not to let this happen to anyone else'.

'not to let this happen to anyone else'

Background



Malignant mesothelioma (MM) is an aggressive, rare cancer caused by exposure to and inhalation of asbestos¹⁰. Incidence is higher in certain occupational

groups including asbestos mining, and disposal and construction industries¹¹. These industries are male-dominated and as a result the disease itself disproportionately affects men (83%). Since 1991, Landrigan and others have posited the idea of three waves of asbestos disease¹²⁻¹⁶. The first wave was seen in countries with asbestos mining operations. The second resulted from the use of asbestos-containing products and its use in construction. This second wave is that which is most associated with mesothelioma in the UK and its link primarily with men working in the construction industry. The third wave, they suggest, would be seen in those exposed to asbestos in the environment, exposure to asbestos in place. Exposure in hospitals could constitute part of such a third wave.

The UK has the highest rate of mesothelioma in the world^{17,18}, with a deaths per-million per-year rate of 68.1 for men and 12.9 for women¹⁹. The death rates increase with age, with most dying in the over-75 categories. Contrary to the notion of a third wave, a case-control study of mesothelioma risks concluded, 'There was little or no evidence of increased risk in non-industrial workplaces such as schools or hospitals after excluding those who [had] also worked in higher risk jobs'¹⁸ p.44.

This conclusion is controversial for at least four reasons:

- 1) As stated above, the death rates increase with age, with most dying in the over-75 categories. The Office for National Statistics does not record the occupation of the deceased in the over-75 category; given the slow rate of growth of the disease, particularly where exposure is relatively low-level, this is likely to mean that those exposed in some environments such as schools and hospitals will not be recorded as such.
- 2) It is not always clear in the data that someone has worked in a healthcare environment; this is particularly the case if they are recorded as engaged in ancillary work, such as portering, cleaning or laundry work.
- 3) The ONS records only the final occupation of the deceased; teachers and nurses who went on to other careers will not be recorded as such.
- 4) Howie undertook an examination of the ONS data alongside data on numbers of teachers and nurses employed in a period from 1960-1980²⁰. He writes:

Given that 125 teachers and 66 nurses up to age 74 died from mesothelioma over the period 2002-2010, teachers and nurses experienced about four and two times higher mesothelioma deaths respectively than would be expected from typical asbestos fibre concentrations in buildings containing asbestos-containing materials in good condition. p.36.

Howie adds that as deaths are only recorded to age 74, this may well underestimate the discrepancy. [See Appendix 1 for a summary of Howie's method.] Furthermore, given that almost all NHS hospitals contain asbestos, there is concern that cases of mesothelioma in hospital could increase over time²¹.

Teachers and nurses experienced about four and two times higher mesothelioma deaths.

Design

A mixed method design that included three stages preceded by a stakeholder consultation.

They gave their views on presentation, diagnosis, treatment and care for healthcare staff with mesothelioma.

Stakeholder consultation

The research team brought together a range of staff and professionals working with healthcare staff with mesothelioma. These included health professionals (consultants, clinical nurse specialists, family members of healthcare staff with mesothelioma and others), people from asbestos support groups and charities, as well as welfare and legal professionals. They were identified via Mesothelioma UK and partner organisations. In the consultation process, they gave their views on presentation, diagnosis, treatment and care for healthcare staff with mesothelioma following workplace exposure to asbestos. They also provided more specialised information, such as data on prevalence of mesothelioma in healthcare staff. In some cases, they liaised with Mesothelioma UK to present information about the study to potential participants in the interviews.

Stage one: A rapid literature review

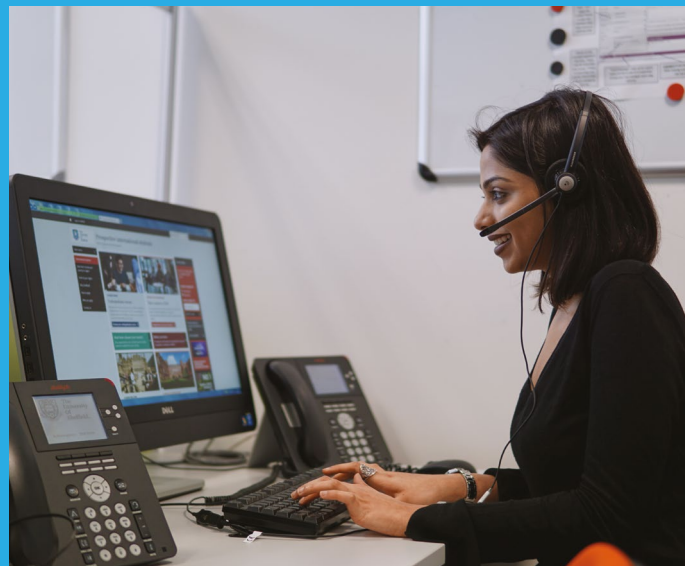
A rapid review is conducted when a systematic review is either unnecessary or impractical. It uses the principles of systematic review insofar as the search is replicable and thorough but with time-limited formal quality assessment and searching²². The question for the review was *“What are the experiences of presentation, diagnosis, treatment and care for healthcare staff with mesothelioma?”*

Stage two: A freedom of information request

Given the limitations of ONS data on mesothelioma deaths noted in the ‘Background’ section above, it was decided to make a Freedom of Information (FOI) request relating to the level of mesothelioma amongst current and former healthcare staff, primarily in the NHS. This was to be judged via the indirect but available route of asking for the number of legal claims made by former or current staff against the NHS relating to mesothelioma caused by negligent exposure to asbestos whilst at work.

Stage three: interviews

Semi-structured interviews were undertaken with healthcare staff diagnosed with mesothelioma or with their partners; the purpose was to gain insight into the experiences of presentation, diagnosis, treatment and care.



Stage one: Rapid Review of the Literature

I Background

This (rapid) literature review was conducted in August 2019, examining the experiences of healthcare staff with mesothelioma. A rapid review is conducted when a systematic review is either unnecessary or impractical. It uses the principles of systematic review insofar as the search is replicable and thorough but unlike systematic review, it has only time-limited formal quality assessment and searching²². The question for the review was 'What are the experiences of presentation, diagnosis, treatment and care for healthcare staff with mesothelioma?'

II Method

A literature review examining qualitative studies of the experience of people living with mesothelioma was published in 2010 using literature up to 2008²³. That review identified 13 articles published from 1980-2008: five qualitative²⁴⁻²⁸, five QoL data²⁹⁻³³; two cohort studies including MM^{34,35} and a survey³⁶. These were checked to see whether they had specific information on the experience of healthcare staff. The method used to do this involved using the advanced search facility in Adobe: the individual terms 'colleague, doctor, healthcare, health [proximity 10] care, nurse* and physician'. None of the papers had specific information on the

experience of healthcare staff; they were therefore excluded.

The next stage was to update the 2010 review for literature from 2008 to 2019. Databases searched were Medline, Cinahl, and Web of Science using the search terms 'patient experience OR patient narrative OR patient stories OR patient story OR patient perspectives OR patient perceptions OR psych*' AND mesothelioma. PsycINFO was also searched simply using the term 'mesothelioma'. This gave 832 records. The same terms were used in Google Scholar and the first 1,000 items were checked for additional articles. This gave a total of records screened of 1,127 (see PRISMA chart). 1,090 were excluded on the basis of title and preliminary information. The remaining 36 were assessed as full-text^{3,6,7,37-69}. A PRISMA chart is available at appendix 2.

These 36 were checked using the same Adobe advanced search facility as described above. Two had specific information on the experience of healthcare staff^{6,7,56}. In addition, one article had a doctor with mesothelioma as an author but no specific information relating to her experience as such³. There were also five items of grey literature plus two YouTube broadcasts; these were provided by colleagues in the mesothelioma research community^{2,4,5,8,9,70,71}. This gave a total of 10 relevant items on the topic of the experiences of healthcare staff with mesothelioma^{2,4-9,56,70,71}. These concern doctors and nurses; no information was found concerning

the experience of other healthcare professionals or staff. A number of items were found concerning dentists and dental technicians but were excluded because they had little information on the experience of mesothelioma, being focused instead on the danger of asbestos⁷²⁻⁷⁵.

Three of the 10 relevant items are not readily accessible in transcript form and so have been included as appendix 3^{2,5,71}. We recommend that readers interested in exploring the findings of this review in more depth read these and the other seven relevant items.

There is, in addition, a small amount of literature based around the experience of physicians who become patients. Where this experience concerned mesothelioma, the literature had already been found in the items above. The remaining literature was briefly examined for relevance. Most relates to doctors as physicians, with two books of anecdotes and discussion^{76,77}. Amongst the remaining literature were discussion, review and education articles^{37,78-81} as well as primary research⁸²⁻⁸⁷. Discussion of the experiences of nurses was more sparse but a useful literature review is provided in the thesis from Pucino⁸⁸. No literature was found specific to the experiences of other healthcare professionals or healthcare staff (although it should be emphasised that this section of the review was not a systematic search).

III Findings

The findings are reported in three sections. The first is a brief overview of evidence relating to health carers as patients; the second is an overview of the evidence relating to patients with mesothelioma; and the third is a fuller review of the evidence relating to health carers as patients with mesothelioma.

a) Health carers as patients

A central finding related to the notion of control (sometimes termed locus of control). In the case of doctors 'control' seemed to relate to the switch from being directors to recipients of healthcare. The accounts in the literature revealed that doctors used various strategies to maintain control, such as informal discussions with a range of consultants. Ironically, this sometimes resulted in suboptimal care through deviation from the normal pathways, conflicting advice and the exclusion of GPs⁸². From the viewpoint of those caring for doctors, the process can be difficult; such patients can be seen as demanding^{78,86,87}. Despite guidelines suggesting that healthcare professionals should be treated the same as any others, in practice this is difficult to do; there is a desire to do the best possible and to go off-piste, for example, through providing home contact details⁸². In the nursing literature, the loss of control is associated strongly with feelings of vulnerability and fear. This seems to be related to noting a lack of compassion and support from fellow nurses. Some nurses even noted mistreatment. There was also a feeling that the nurse as patient was being avoided by the nurses caring for them.

The desire to maintain control, alongside so-called corridor conversations and the tendency to interpret symptoms benevolently sometimes resulted in late investigation and diagnosis⁸⁰. In addition, Tomlinson notes that when the time to give a serious diagnosis arose, doctors were reluctant to do this to other doctors⁸¹; this is a problem noted with force by Sweeney in relation to his own diagnosis of mesothelioma^{5,6}.

The culture of medicine was noted as causing problems for some; there was an expectation that doctors would be able to cope and that they were in some way immune from disease⁸⁵. In addition, both nurses and doctors noted a feeling of guilt or of being an imposition on fellow professions^{79,88}.

The final issue worth noting is that both doctors and nurses had some anxieties about confidentiality and privacy, about their case being discussed widely with other healthcare professionals^{79,80,88}.

b) Patients with mesothelioma

Before looking at the experience of health carers with mesothelioma it is worth first looking at that of patients in general with mesothelioma. There is a body of literature here, reviewed by Moore et al²³ and by Bonafede et al⁶⁹. In addition there is a review with case studies by Buchholz³⁸. Moore et al and Bonafede et al categorise the impact of and experiences related to mesothelioma as physical, emotional and social. Physically, the condition has a substantial impact with a high symptom burden, particularly of pain and breathlessness.

Emotionally, the impact is perhaps even greater, with high levels of fear, anxiety, depression and feelings of isolation; anger is also noted, although this may be greatest in relatives acting as carers. In this regard, it is worth noting also that the emotional impact on carers and families is also large. Socially, patients noted the impact in terms of changes of role, such as loss of work, changes in relationships, such as increased dependency on partners, and in terms of increased social isolation. In addition, patients and relatives commented on the experience of care. The Moore et al article draws on a survey by the British Lung Foundation to note that, in general, patients were positive about the care they received; carers were more critical. Both Bonafede et al and Buchholz emphasise the emotional and psychological needs of patients, and Buchholz examines the recommendations for treatment in relation to these needs. Chambers et al review literature related to the effect of stigma and nihilism on lung cancer outcomes³⁹. Stigma is related to criticism of smokers who get lung cancer and as such, is not noted as relevant to mesothelioma; by contrast, the nihilism of healthcare professionals treating mesothelioma has been recognised⁸⁹⁻⁹¹, most recently by Warby et al⁶³. The term 'nihilism' conveys the sense that clinicians act or feel as though there is nothing they can do for people with mesothelioma.

c) Health carers as patients with mesothelioma

Some caution is due regarding the evidence used to highlight the experience of health carers with mesothelioma. In the first place, none were formal pieces of research. In addition, many had a specific purpose, for example, to highlight the importance of good communication, to raise awareness of the danger of asbestos in hospitals, to express criticisms of the NHS prescribing policies in mesothelioma and so on. Despite this, the evidence does include useful information on the experience of healthcare staff with mesothelioma. Indeed, the blog written by Mags Portman runs to around 20,000 words, beginning around the time of diagnosis in February 2017 with a final entry on 5 October 2018. During this time, she reports her experiences of chemotherapy, surgery, remission, illness resumption and immunotherapy.

However, this leads to a further caution. The evidence reports the experience of three doctors and four nurses, not of any other healthcare staff, for example ancillary staff and allied health professionals. In addition, the three doctors were highly experienced, thoughtful and probably exceptional, as is particularly clear in the case of Mags Portman. There is a need to report evidence from a wider range of healthcare staff, as we do in the interviews reported below.

With those caveats we can begin by examining the extent to which the three doctors and four nurses reported experiences that were

also seen in the group of patients with mesothelioma in general, reported above. These fell into three categories, physical, emotional and social.

i) Experiences shared with other mesothelioma patients

Physical: In most of the items reviewed, the physical experience of mesothelioma was not a focus. The exception to this was the Mags Portman blog. This had a number of references to physical symptoms. At first, these related to symptoms on and around the initial diagnosis of the disease.

I had also noticed that I was increasingly short of breath and fatigued. I was short of breath when walking on the flat. I was short of breath reading my kids their bedtime story. Not that I would ever admit that, EVER. The pain below my right shoulder blade was there constantly and really quite prominent in the evenings ².

As time went on, particularly in periods of relapse, pain could be extreme. There were, in addition, other "horrible symptoms [...] like an increased gag reflex on taking tablets or cleaning my teeth, sometimes making me vomit", and "waking up during the night with seats and chest/back pain [...] having to take extra morphine."

In June 2018, this worsening symptomatology was finally relieved by a change in treatment. Overall, it seems likely that the physical symptoms experienced by health

carers will be similar to those experienced by others. However, for health carers who have specific medical knowledge, the awareness of the significance of symptoms might have an effect on how they are perceived, hence the anxiety just referred to.

Emotional: In one of Mags Portman's blogs, she writes that she has spoken a lot about how it feels emotionally, less about physical symptoms. In the material from the other health carers, emotional effects were to the fore. Anger, fear, depression and more are reported; Dr Sweeney said,

I was so upset about what had happened ... I am a man devoid of hope ⁵.

Bitterness is also evident in this quote from Dr Lawson, regarding the cost of a treatment that was not provided by the NHS,

Mind you, £30,000 is a lot of money to waste on a very sick person. You could, for example, employ for nearly a year a 'senior parenting practitioner' in the London borough of Tower Hamlets ⁸.

In several cases, there was a sense of irony attached to the likelihood that the disease was a result of exposure to asbestos at work, when that workplace was there to provide healthcare. This is something that may not be present with others who were exposed to asbestos at work. There is also some fear and anxiety, both of the illness, of death and of the welfare of those left behind.

All I could think was “My kids. My beautiful, beautiful children...

My main concern was for my kids, how to speak to them, what support was available for them ²?

Against this there was also the response often referred to in other cases of cancer and serious illness, that of determination, as with this nurse’s comment:

When I was told I had a terminal illness I didn’t think I’d see last Christmas. But here I am, and am fighting it. I can’t let it beat me ⁵⁶.

Social: The social impact of the mesothelioma diagnosis was felt widely. Dr Sweeney introduces the idea well:

What I have always feared in illness was anonymity, being packaged, losing control, not being able to say ‘this is who I am.’ In the end, one is left alone, here, in the kingdom of the sick ⁶.

Mags Portman also refers to the role change on several occasions. These social impacts move us on from experiences that these doctors and nurses shared with other mesothelioma patients to those that were more specific to them as healthcare professionals.

ii) Experiences specifically relating to healthcare staff with mesothelioma

Problems with communicating with a sick colleague, when that colleague is a fellow healthcare professional, were widely reported.

Problems with communicating with a sick colleague, when that colleague is a fellow healthcare professional, were widely reported. Dr Sweeney is particularly concerned with this. He notes on several occasions that he was never formally told his diagnosis, only seeing it unequivocally from reading his notes. By contrast, Dr Portman’s experience was, she felt, overly direct because of her medical knowledge. Dr Lawson also criticises over-directness.

Perhaps the radiologist who rang me up at home to tell me my CXR showed I had cancer and would I like to come in for a CT could have been a bit more subtle ⁷.

Dr Sweeney is critical also of what he describes as a crass attempt at humour by a fellow health professional involved in his health care.

But I’m sitting there with a plastic...green plastic bag, holding my clothes, hoping the back of my gown was closed, when a senior radiographer walked briskly into the patients’ area and said, Kieran Sweeney, follow I... But this crass attempt at humour, follow I, just humiliated me. I felt just utterly degraded. I felt seriously upset by it.

That he should so trivialise what was for me a shocking passage into my healthcare problem; I’m so angry about that ⁵.

There were other criticisms made of care and communication. For example, Dr Sweeney says:

The most insensitive observation I am compelled to make is that the more junior ranks of ancillary health professionals are simply unable to conceal the pleasure of the deployment of their authority ⁶.

Dr Lawson is the only one to report concerns about the technical care given.

Call me old fashioned, but when a patient says, “Do you know that as a consultant anaesthetist of some years, I have always found it is helpful to wait for the local anaesthetic to work,” the response should not be to just push harder ⁷!

By contrast, both Dr Portman and Dr Sweeney felt care was good technically.

The notion of locus of control is manifest, with patients seeking to keep control over their care.

For Dr Lawson, being a senior medic in the NHS presented opportunities for him that were not available to others. In several places he and his partner comment on the inflexibility of the NHS for most patients. In comparison, he could use the system to get more choices of other treatments; in part this was due also to finance and insurance he had available to him. Dr Lawson says this leads onto an ethical concern. Having found out about a new but unproven treatment available in the US, his UK oncologist refused to administer it because “we won’t know whether the chemo has worked”. He reflects that the scientific knowledge should not be the primary concern of the practitioner at that point.

Dr Portman is more positive both about the NHS and about clinical trials, doing a specific YouTube broadcast saying so.

The specialist knowledge of the three doctors was apparent and made a difference to their experience.

So, I did what I could do, and contacted a previous colleague and friend, a Consultant in Respiratory Medicine. I felt uncomfortable about doing this,

and was aware that this opportunity was only available to me because I was a doctor. How on earth did other people cope with being in limbo-land? I was able to justify my actions to myself, because I knew that if a colleague contacted me for help, I would do my utmost to support them ².

There was, however, also the danger of the professional assuming too much knowledge of the person with mesothelioma:

The radiologist ASKED ME if he should give me anything for allergy. How would I know? The joy of being a doctor patient ².

One final issue worth raising is that of confidentiality. It is clear in some of the reports that staff are aware of the mesothelioma diagnosis in a colleague, see, for example, Sweeney’s transcript. Dr Portman raises the concern explicitly:

“Your X-ray’s not requested on the system. Nothing’s ever straightforward when it’s you doctors,” says the receptionist. Great. How did she even know I was a doctor ²??

IV Discussion

To summarise: in the evidence reviewed, healthcare professionals with mesothelioma report experiences shared with other patients with the same condition, physically and especially emotionally. They also report social issues relating to the change in role from professional clinician to patient. Like other health carers who become patients with conditions other than mesothelioma, the notion of locus of control is manifest, with patients seeking to keep control over their care through, for example, using colleagues via unofficial channels. There is a hint of some concern over confidentiality and privacy. In addition, there was a large amount of criticism of some of the care given, particularly related to communication of, for example, diagnosis. Dr Lawson raised specific concerns about the ethics of RCTs and rationing ¹.

Stage two: A Freedom of Information (FOI) request

I Background

The purpose of the Freedom of Information (FOI) request for MAGS was to get a better idea of the level of mesothelioma amongst current and former healthcare staff, primarily in the NHS. As stated earlier in this report, there are several reasons to believe that ONS data on mesothelioma deaths linked to occupation are unreliable; and some authors dispute the ONS conclusion that there is no evidence of increased risk in schools or hospitals. Also disputed is the claim that levels of mesothelioma in the UK will start to fall, now that the known high-risk occupations are largely protected.

The BBC put in a FOI request in 2018, linked to this news item ². The journalist, Nicola Hudson, kindly provided fuller details in an email. In the period January 2013 to December 2016, they found 352 claims against health trusts in Great Britain by people who have developed asbestos-related disease in NHS buildings. The FOI request was to individual Trusts, 87% of whom responded. 182 claims had been settled at a mean average of £25,824. One problem with this data from our viewpoint is that it concerns a broad category of 'asbestos-related disease' rather than mesothelioma.

II Method

The MAGS FOI request took a different approach. Some lawyers involved with the project or with other mesothelioma work were struck by the apparently low levels of mesothelioma in NHS staff in the ONS data. In some cases the lawyers observed that they were aware of more cases linked to their own practice than the ONS data showed for the whole of the UK. We therefore put in an FOI request to NHS Resolution, which is the body that deals with litigation in the NHS, including negligence claims. On 3 September 2019, we made the following request.

Information Request: I am a researcher undertaking a project for the charity, Mesothelioma UK. I would like to know about civil law cases of negligence that have been taken against the NHS with regard to current or former NHS employees who have developed mesothelioma and have sued because they believe it to be due to asbestos exposure at work. I would be interested to know cases in the last 15 years (or less if information is available but not for that period).

Any information would be helpful but, if possible, I'd like to know, for each year: i) Number of cases received; ii) Number of cases settled in favour of the employee, number of cases with out-of-court settlement and number of cases settled in favour of the NHS.

I would also like to know (again, if information is available): iv) employee type; v) employee gender.

The response came in two stages. The first gave the information for points i-iii but said that iv and v could not be provided because of concerns about data protection; the low numbers in each year gave rise to the possibility of individuals being identified. We therefore revised the request, saying we would be happy to receive information on employee type and gender for the whole period available rather than for each year. On this email request we also asked for confirmation that the coding string used related solely to mesothelioma.

The response (see appendix 4) confirmed that the coding string did relate solely to mesothelioma. They provided data with a gender breakdown but were unable to provide occupation/employer type. This would need to be conducted manually and NHS Resolution required payment for this. We anticipate the cost would be £1,150. This information would help Mesothelioma UK to better understand occupation and workplace of people who develop mesothelioma working within the NHS. It would also inform the development of any recommendations or awareness-raising materials.

² <https://www.bbc.co.uk/news/uk-england-45561384>

III Results

The full response so far is set out in appendix 5.

The following points are worth highlighting:

- Between 2002-15, the ONS recorded 177 deaths of NHS staff due to mesothelioma.
- By contrast, between 2004-17 there were 961 claims made against the NHS for negligence (with regard to asbestos) that has resulted in mesothelioma. Of these, 553 were successful. This almost certainly understates the extent of the problem as in this study alone, we have become aware of cases where NHS staff with mesothelioma have not been able to pursue a claim because they had insufficient evidence of negligence. The legal threshold is a greater than 50% chance of winning; this cannot be achieved by, for example, a nurse who has worked in several places and has no memory of a specific exposure, such as working next to a ward where asbestos was removed. The FOI indicated rates of female deaths and claims are higher than for men; this is an unusual pattern in mesothelioma statistics. In addition, the rate of claims is increasing.

As noted already, we do not know the breakdown by occupation. In particular, it would be helpful to know whether professional or ancillary staff are more likely to make a legal claim.

Finally, there is an issue raised by one of the legal professional stakeholders who helped with this project. It is that the average levels of compensation in these figures look very low. NHS Resolution has confirmed that these are all cases of mesothelioma and, as such, this point is a puzzle. It is also puzzling that Table 3 shows some claimant costs paid in cases that were resolved in favour of the NHS rather than the person with mesothelioma; the amounts are small but it is hard to understand why there would be anything paid. However, if we take the total number of successful claims, 553, and divide by the damages paid, 19,565,492, we get an average figure of £35,381. This is £10,000 higher than the BBC figure for 'asbestos-related disease' claims, but the legal professional stakeholder says this is much lower than they would expect.

IV Discussion

The FOI request might be worth repeating annually as it would enable us to track the pattern of claims; if the number of claims carries on rising this would support the assertion that cases of mesothelioma have not peaked; it would also support the argument that hospitals are not low-risk environments.

It would also be worth considering whether to put in another request for the data on cases broken down by occupation. According to the email cited above, this would cost $46 \times 25 = £1,150$. In addition, it might be useful to ask NHS Resolution for the amounts paid in damages, perhaps as a spread from lowest to highest. It seems unlikely that they would be able to provide more, for example, on what the average amounts are by profession. This may need investigation via another route.

Between 2004-17 there were 961 claims made against the NHS for negligence (with regard to asbestos) that has resulted in mesothelioma.

Stage three: Semi-structured interviews

I Background

The rapid literature review reported above found no specific research examining the experience of healthcare staff with mesothelioma. This work is therefore, the first example. Like the rapid review, the interviews sought the experiences of presentation, diagnosis, treatment and care for healthcare staff with mesothelioma.

II Method

Current or former healthcare staff diagnosed with mesothelioma were invited to take part in semi-structured interviews. The invitations were sent via Mesothelioma UK and associated contacts. There were five interviews completed; three with former nurses, one with a former

GP and one with a former healthcare assistant. Their ages at time of interview were 61, 82, 72, 75 and 75.

One person approached decided not to take part. Interviewee #5 asked that no quotes be used. Interviews #7 and #8 were with partners of two healthcare workers, a GP and a healthcare administrator. Both were also accessed via Mesothelioma UK. The GP had died within a few months of diagnosis; the healthcare administrator survived for around three years. Three of those interviewed had been diagnosed for more than three years, one for 18 months and one had been diagnosed within the previous six months. The GP was male, the remainder, female. One of the interviewees sadly died soon after taking part.

Table 1: Characteristics of interviewees

No.	Occupation	Gender	Legal Case	Age	Married	Live with Partner	Time Since Diagnosis
#1	Nurse	F	Yes - settled	61	Y	Partner	1 year
#2	Care assistant	F	Legal case didn't proceed on advice of solicitor	82	W	Alone	5 years - now died
#5	Mental Health Nurse	F	Unsure whether to proceed	72	Y	Partner	4 months
#6	Nurse	F	Yes- ongoing for 3 years	75	Sep	Alone	More than 3 years
#7	Partner of GP	F	Yes - settled	NK	Y	Partner	Survived 3 months
#8	Partner of HC administrator	M	Yes - settled	60 when died	Y	Partner	Survived 3 years
#9	GP	M	Legal case didn't proceed on advice of solicitor	75	Y	Partner	18 months

The interviews took place over the phone and were recorded and then transcribed. Identifying details were then removed from the transcription and the recording deleted. The interviews lasted between 22-58 minutes. Transcripts were then entered onto a computer assisted qualitative data analysis software (CAQDAS) programme (Quirkos®) to support analysis.

III Findings

The interview findings can be placed into the same three categories as were used in the rapid review, above.

a) Healthcare staff as patients

The issue of the loss of control, or change in locus of control, identified in the rapid review was not seen in the interviews; nothing was said of the sudden role change from professional to patient felt by the senior doctors in the review. One senior nurse felt that her knowledge was insufficiently noted by the consultant when discussing her diagnosis. There were also a couple of examples of interviewees maintaining some control over the treatment process such as through deciding the pain-control regime, but these were not beyond what might occur with any informed patient. No-one raised concerns over confidentiality and privacy, as had been the case in the review. However, as in the review, interviewees noted the feelings of avoidance of other professionals,

So, it puts them on their guard. But, at the end of the day, I'm a patient, you know? And it shouldn't be like that. But, sadly it is, you know?... they're just a bit wary you know, 'cause I'm a nurse. Source: #1 Nurse

In addition, there were examples of expectations from staff at how patients who work or worked in healthcare should behave, something we noted as the culture of medicine in the review. The following example arose when the partner of a GP with mesothelioma took her to casualty.

And the casualty doctor turned round and said, what are you doing here; you've got mesothelioma, you need to be at home basically to die. That's what he meant. You know the medical system, you know the diagnosis, therefore what are you doing, you're wasting my time. Source: #7 Partner of GP

We shall return to this particular incident below, in relation to the broader topic of resuscitation. It raises also an issue of the language used by healthcare professionals to their peers as patients. As we shall see presently, the process of giving a diagnosis to such peers is sometimes brutal. The GP interviewee put this as follows,

Which is a bit, again, it's a bit blunt. But I felt she was talking to a doctor, as if it was talking about somebody else... Yeah, it's, you're kind of that one step removed from yourself. Source: #9 GP

Not all respondents had knowledge of the condition. Amongst these, for example, the healthcare assistant and the mental health nurse, there were no concerns expressed about any assumptions on the part of the healthcare staff.

Interviewer: And, did you feel any... 'cause you'd not heard of mesothelioma, was there any, kind of... did you feel as though they were assuming you knew what it was because you were a nurse? Response: No, they didn't... no, they were very kind, he did tell me what it was about and then I spoke to the Macmillan nurse and I've always been able to approach them, they've been very good. Source: #6 Nurse

b) Patients with mesothelioma

On the physical side, symptoms of pain, nausea and breathlessness are spoken of by many of the interviewees. Drainage of the lung brought relief from breathlessness; one partner said he was able to do this at home and that was rewarding for him; this was a nurse whose partner was a healthcare administrator. Having said that, two of the interviewees said their symptoms were relatively mild although both were aware this could change.

On the social side, the loss of work was noteworthy for some, with one nurse calling it one of the hardest things about the illness. The GP carried on working after the diagnosis for a few months that:

I couldn't manage to, you know, carry my weight with working in the unit. So, I just retired. Source: #9 GP

There was also an effect on those who cared for the person with mesothelioma; the partner of the GP noted:

And therefore, I finished work middle of December to actually care for XX because I could see that we weren't getting any support or anything. Source: #7
Partner of GP

Some were able to use their professional skills in helping other patients, both through the clinics treating them and through social groups. Being able to drive enabled social life to continue a little for some. And one respondent had joined a walking group that was specially adapted to those with physical limitations. The presence of family or partners was important for all respondents. The care assistant had two daughters who took her out most days, for example.

The emotional effects of the illness were striking, as they were in the rapid review. To some extent, these effects were altered for many by the fact that they were healthcare staff; we shall therefore turn to them in the next section.

c) Health carers as patients with mesothelioma

Working for the NHS in a caring capacity made a difference to the experience of mesothelioma for most respondents. Some had knowledge of the illness and their response was affected by that. Nurse #1 was amongst those describing the diagnosis using terms like "horrendous"; the GP (#9) described himself as devastated by the diagnosis and that he knew the implications. For the healthcare administrator, this was less the case but his partner, a nurse, reported:

And then when [Pt name] went out of the room to have his blood test and his weight done and everything, the consultant said to me, he said to me, it's a bit like trying to hold back the tide, he said, you can hold it back for so long, but eventually it will take over and he will die. So then after all that, we got home and I think that's when it hit [Pt name], because he was in tears really and saying, I don't want to die, I don't want to die... Source: #8 *Partner of HC administrator*

Knowledge of the link to asbestos caused some confusion for two of the nurses (#5 and #6) as they were not aware that their work exposed them to any potential danger. This was also the case for the consultants in at least one case.

[We] had consultants that wouldn't accept that she wasn't suffering from something normal. Mesothelioma should be sort of kept at the back of everybody's mind, I think. It's not the first port of call, but when you've got something strange and you don't know what it is you can't rule it out. And the consultant I think said it couldn't be some things because she hadn't worked in industry. Source: #7
Partner of GP

The healthcare assistant (#2), however, described herself as not being shocked.

I just accepted what he said. Well, you do when a doctor tells you something, you accept it don't you?
Source: #2 *Care assistant*

But goes on:

But I didn't sleep that night, I remember not sleeping. And I kept thinking, 'cause when he said, where did you work? And I kept thinking, well where could I have had it from, you know? Source: #2 *Care assistant*

Two other respondents reported how their healthcare team tried to trace asbestos exposure through other causes, such as their own or their partner's previous work.

One respondent said that the presence of Macmillan nurses at the point of diagnosis was disconcerting as he knew this meant the diagnosis would be cancer. This is recommended in practice and the respondent was not suggesting it should not occur, only that practitioners might know the implication.

As well as knowledge of the condition, some interviewees had expectations of the NHS itself; and a major theme through most of the interviews was disappointment at the way it operated for them. In the first place, some found that the diagnosis was given to them in an overly brutal fashion. The GP (#9) was told he had nine to 12 months to live and that there was no treatment because chemotherapy doesn't work (a view also held by the GP in the interview). Nurse #1 reports:

[The] Lung Nurse Specialist, when I came out of that office, after the consultant telling me I had mesothelioma, she said, I'm going to hand you over to [**] our Lung Nurse Specialist now. And I literally went into a room with her, shell shocked, and all she did, she just said, I'm so sorry about your diagnosis, take these, and if you do nothing else, then ring this number. And that was it. I walked out, I thought, I've just been told I've got a terminal illness, and all I've got is a bunch of leaflets. Source: #1 Nurse

The same nurse suggests that one problem here is the lack of nurses specialising in mesothelioma; as the quote above makes clear, her own diagnosis was given by a nurse that dealt with a range of lung disease, mesothelioma rarely featuring. The GP's partner drew a link with Andrew Lawson's experience, reported in his articles.

The one from Andrew Lawson I thought was actually quite poignant really, because some of the experiences we had are quite similar in that doctors...explaining to other doctors that they're ill is not very good actually. It can be very, very brutal when you're not expecting it... The scan showed a massive lump and things. The consultant just turned to her and showed her the scan and said, this is bad, you understand this. And XX she could see that it wasn't correct. But that was it. Source: #7 Partner of GP

There were other disappointments, particularly in the standard of care, as reported above (a) Health carers as patients. While all patients may potentially feel this, health carers may set this against the standards they know should apply or that they would apply.

Another disappointment, highly specific to NHS staff, was that they had picked up mesothelioma from work.

And I thought, never in a million years would I have told a patient, or spoken to a patient like she did. Source: #1 Nurse

There was also praise for the care received, sometimes of particular units, such as the chemo unit, or of particular carers. The mesothelioma specialist nurses came in for praise, for example. Other respondents mentioned particular acts, such as teaching the partner how to do the lung drainage at home, helping with benefits claims and putting them in touch with solicitors, or with other caring organisations and charities. The latter were also highly commended by some correspondents.

Another disappointment, highly specific to NHS staff, was that they had picked up mesothelioma from work.

I think personally now, it's ironic, that I've dedicated 44 years of my life, and you know, that dedication is what's killing me now. It's ironic really. Source: #1 Nurse

I was a bit angry and upset, but I've worked through it now and, you know, I just carry on. Source: #6 Nurse

One other source pointed out that her likely exposure was in a place where patients stayed long term such that they, the patients, were also at risk. A similar point is sometimes made about children in schools where teachers have been exposed to asbestos and developed mesothelioma.

This sense of irony and anger was compounded in some cases by the way the NHS responded to legal claims. Some interviewees felt this was unnecessarily slow and obstructive.

Now, what actually happened was that they were putting freedom of information requests and things to try and find out what they were doing at that period of time. And they wouldn't respond to us, so we got to the point of going to court. And one week before the court date, which they had put back a number of times, possibly even a couple of months actually, they suddenly delivered ten box files to [lawyer name]. And within one of the box files was a letter basically saying on a certain date, when [XX] was present, they were refurbishing the foyer, removing asbestos ceiling tiles. And they presented that to them and said got you. They said okay, and we settled out of court. They had the information but they hid the information and they wouldn't accept anything until we basically proved that they were doing something. Source: *#7 Partner of GP*

In one case (#8) the person died before the claim was settled. The partner describes the process of making the claim as 'horrendous' and 'a battle'. He also praises the legal team on their side, a feeling echoed by other interviewees. It should be noted that in two cases, the lawyers decided not to proceed with the case. This decision is made on the basis of whether the legal team is able to insure itself for the cost of their work if the claim fails. The insurance companies only accept such a risk if they consider there to be a greater than 50% chance of success. In the two cases that did not proceed, the interviewees felt nonetheless that they had been exposed to asbestos at work. One interviewee expressed disappointment as she read of other cases that had proceeded and seemed similar to hers.

There was one other way in which, as one interviewee put it, the system 'just didn't work'. Above, we quoted an example of the person with mesothelioma going to casualty with an exacerbation of symptoms and where the casualty doctor told her:

You've got mesothelioma, you need to be at home, basically to die. Source: *#7 Partner of GP*

Another interviewee reports:

I said, well, can I call an ambulance, and she said, well, there's no point because the ambulance won't take him because he's signed a do not resuscitate form. So that was traumatic. Source: *#8 Partner of HC administrator*

The latter interviewee also reported not being involved in the non-resuscitation decision. We return to this issue of non-resuscitation decisions in the discussion section below.

The issue of research trials did not feature highly in the interviews. One person had turned down participation in a trial. And one had been entered onto an immunotherapy trial, which had worked well for a period of time before serious complications caused them to withdraw. Most interviewees reported receiving standard treatment, not within a trial. The GP in the immunotherapy trial said that if he had been randomised to the arm he did not want, the chemotherapy rather than immunotherapy, he would have withdrawn after a month

I would have gone for a couple of doses of chemotherapy, and then regarded that as a failure, and then looked for a study of people that had failed chemotherapy. Source: *#9 GP*

There were few other examples of interviewees 'playing the system'. In one case, a GP from the same practice where the person with mesothelioma worked was called upon to discuss, and change, the treatment being given. And in general, interviewees were able to understand the processes perhaps quicker than lay people would.

All interviewees were asked whether they had had any information or training regarding asbestos risk in their workplace. None had done so formally. When specific incidents had arisen, such as the demolition of a building, there had still been no information, even where staff in safety gear were present. The interviewees felt that it should be part of the induction package for new healthcare staff and, perhaps, also for older staff as they leave for other work or into retirement.

IV Discussion

This study is the first to focus on the experiences of presentation, diagnosis, treatment and care for healthcare staff with mesothelioma. As a mixed method study, it is able to combine knowledge of the prevalence and incidence of mesothelioma in healthcare staff with experience-based interview findings.

Out of the seven interviews, only one concerned an administrative worker, and none were with ancillary staff such as porters and laundry and maintenance staff. This group is certainly amongst those who have been affected, according to the lawyers in the stakeholder group and some published evidence from as early as 1970⁹². The remainder were with, or were with the partners of, four nurses, one care assistant and one GP. One of the nurses was a mental health nurse.

Even with the exclusion of a large group from the interviews, the interviewees here represented a wider range than that found in the literature review, where senior doctors are the main voice. With the wider range comes the appearance of a range of experience. The healthcare assistant and the healthcare administrator perhaps reported an experience closer to the lay person (although the latter is altered by the fact that his partner was a nurse). Similarly, the mental health nurse and nurse #6 did not have knowledge of this area and do not report assumptions of knowledge being made. It seems reasonable to speculate that the experiences of ancillary staff will also be close to the lay public as reported elsewhere^{23,40}.

In a similar way, the physical effects of mesothelioma were the same for healthcare staff as any other patients. Some, however, have a greater understanding of their significance, which might affect how they are felt. On the social side, the loss of role is important to some; this can be offset with the use of healthcare skills in new roles within, for example, support groups. The fact that the sample here was predominantly nurses or care assistants might explain also the absence of the concern about the locus of control seen in the literature review. It might be that doctors feel this loss of power more strongly than those who have less power in the system anyway. And as with the healthcare staff in the review, the emotional impact of the diagnosis and treatment was profound.

The predominant different factor between healthcare staff centred on the health service.

The health carers and their partners had a critical eye for the care they received, good and bad. There were problems noted with the diagnostic process and lack of specialist support. Some of these mirrored those that were shown in the rapid review, such as lack of support during a sometimes-brutal diagnostic process. This poor communication between healthcare professionals and their peers was noteworthy and mirrors that found in the literature review.

We noted in the literature review above the phenomenon of clinician nihilism with regard to mesothelioma, the sense that they felt there was nothing they could do for those diagnosed. Two incidents reported by interviewees convey this. The first was the GP told that she shouldn't have attended A&E; the second was the healthcare administrator told that an ambulance would not come because of the non-resuscitation order. Here, the Joint Statement on resuscitation is authoritative and helpful⁹³. The report emphasises the following point (p.10, ss 5.1):

A decision not to attempt CPR applies only to CPR. All other appropriate treatment and care for that person should continue.

As such, if it is in the interests of the person with mesothelioma to attend A&E, or to receive an ambulance, or any other healthcare, it should be given. The guidelines also make clear that a readily reversible potential cause of death, particularly choking, should generally be treated.

The Joint Statement also discusses decision making around non-resuscitation orders. Unless the patient lacks capacity, they should almost always be involved in the decision. The patient may choose to include others, such as partners; and these others may formally be involved where the patient lacks capacity. In one of the interviews, the respondent says he came back from the canteen to find that his partner (the person with mesothelioma) had signed the order without his involvement. This is not necessarily against the Joint Statement guidelines, although the timing suggests it might have been over-hasty.

Finally, of the seven people with mesothelioma reported here, three had settled legal claims, one out of court. One had not yet decided whether to proceed. Two had taken legal advice and been told they could not proceed. To win a claim requires showing a specific incident or incidents in which the employer had been negligent. The presence of asbestos is not sufficient. In the FOI section reported above, we found that 961 cases were made against the NHS. The actual number of healthcare staff who have

developed mesothelioma is certainly higher than this but we do not know from any data in this study how much higher. The ONS figure of deaths due to mesothelioma used inter alia to judge the risk level of mesothelioma and other asbestos-related illness to healthcare staff (for example, by the HSE¹⁹) is clearly not fit for purpose.



Recommendations

A number of recommendations have been generated based on the combined findings of the literature review, FOI data and interview study. The recommendations are made with caution in acknowledgement that there are limitations of the study. For example, i) we do not know the occupations of the cases reported in the FOI data, and ii) the sample size for both the review and interview study was small. However, ongoing discussion with a group of stakeholders has helped to strengthen the study and confidence with which the recommendations are made. The recommendations regarding treatment and care presented here largely accord with those given in relation to all patients with mesothelioma. Others are more specific to healthcare staff, such as those relating to education.

- 1) In terms of communication of a diagnosis, the Radio-Meso project offered ten tips for practitioners that would clearly apply for healthcare workers being diagnosed with mesothelioma ⁶⁰. Note, for example, the recommendation not to rely simply on written information and booklets. The eighth recommendation, to be direct and honest, perhaps needs a caveat for healthcare professionals, particularly doctors and nurses, with mesothelioma. This is that the person is a patient first, a professional, second. Unless the person with the diagnosis is actively encouraging it, they should not be spoken to as though they were another member of the team, with potential bluntness regarding diagnosis and prognosis.
- 2) Like other staff, those who have worked in healthcare may feel a loss of role that goes with giving up or reducing work. For health carers there is some potential alleviation in using their skills to help fellow patients, for example, through support groups.
- 3) The healthcare team must understand the Joint Guidelines on resuscitation and the implications, therefore, of a non-resuscitation order. In particular, such an order does not close down any other treatment options or clinics, such as A&E or ambulances. An attempt at resuscitation itself may be appropriate in some circumstances, such as choking.
- 4) The diagnosis of a terminal illness does not automatically lead to a non-resuscitation order; nor does it lead to automatic denial of any services.
- 5) Awareness of asbestos risk should be added to the mandatory training for new members of NHS staff.
- 6) Those staff leaving the NHS should be reminded that asbestos exists in most NHS premises; they should therefore be aware that mesothelioma and other asbestos-related illness is a possibility. In wider education, particularly of GPs, the idea that hospital are low-risk environments should be questioned; mesothelioma should not be discounted in NHS and former NHS staff.
- 7) In terms of future research, this study has not included ancillary NHS staff. We know, however, that some such staff have developed mesothelioma. The indications of this research are that such staff members may not have experiences that are greatly different from other members of the public. As such, it may not be necessary to do further research on the experiences of this group.
- 8) It is, however, important to improve the quantitative data concerning how much mesothelioma there is in the population of current and former NHS staff. The ONS data is a huge underestimate. As such:
 - a. It would be worth repeating the FOI request put in for this report on an annual basis, asking for the number of cases taken by current and former NHS staff in the previous year.
 - b. In addition, the request for a breakdown of the figures by category of staff over a longer period (to comply with data protection concerns) should be repeated until a clear answer is given by the ONS. This recommendation would require financial back-up of approximately £1,200.

- c. Any figure obtained through this route would miss those who had not proceeded with legal cases. An estimate of this might be gained through approaching legal firms and asking them for the proportion of NHS mesothelioma cases they proceed with from all those who approach them.
 - d. Even this figure would miss those who do not approach legal firms in the first place. It is difficult to think of how a figure for this group could be obtained.
- 9) i) The large extent of asbestos contamination in healthcare settings is now well established by research ²¹. ii) The present report has highlighted other data showing that this contamination is causing mesothelioma amongst healthcare workers at a much higher rate than that shown in ONS statistics. Given these two points, the NHS needs to establish better asbestos management processes and systems. In essence, these would have three elements:
- a. Regular testing of healthcare settings for asbestos using new techniques that can detect far lower levels than was possible when the limits set by the Asbestos Regulations 1969 came into force ⁹⁴.
 - b. Track: where asbestos is found, interventions to manage to be implemented, such as provision of protective equipment and removal of the asbestos.
 - c. Prevention: through education of managers and health carers, as set out in points 5 and 6 above.

The NHS needs to establish better asbestos management processes and systems.



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Appendix 1 Summary of Howie's method

Howie undertook an examination of the ONS data alongside data on numbers of teachers and nurses employed in a period from 1960-1980 (20). Here we shall focus on nurses, as exemplars of healthcare workers. He compared the rate of mesothelioma deaths with those amongst people who had not worked in school or hospital environments (or any high-risk occupations). He examines the way the Proportional Mortality Ratio (PMR) is worked out by the Health and Safety Executive using the data. The PMR is found by dividing the number of deaths observed by the number expected for each occupation, the result then multiplied by 100. The figure would be 100 where the number expected equalled the number observed. The significance of the figure is that where it is much higher than 100 the deaths are likely to be the result of asbestos exposure in the industry. For example, the PMR for construction and building trades in the period 2011-2015 was 267.4 with 95% CI 251.7 to 283.9. The figure for nurses is 35.6 (CI: 15.4-70.1). This type of figure leads to the conclusion that hospitals are not places of increased risk. In his article, Howie is working with data from 2002-10, but the official results are broadly similar.

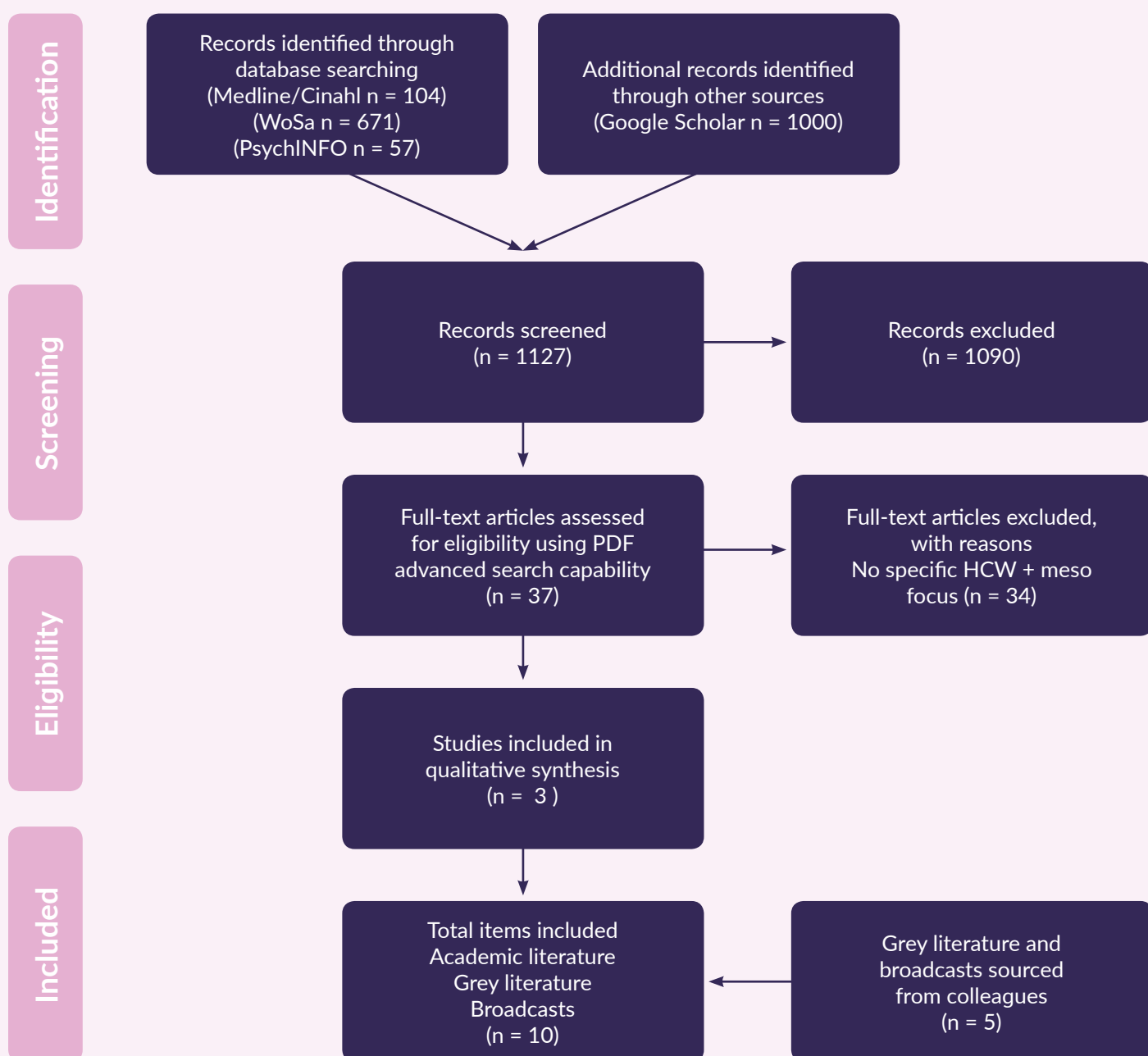
Howie's critical point is that the expected figures are too high. For nurses in the period 2002-2010 it is 87. The observed figures is 64, giving a PMR of 74 (which suggests a lower risk than expected). He cites the HSE (2003) as saying that for hypothetical populations not exposed to asbestos the PMR would be 6 for males and 36 for females. He then uses this figure as the basis for working out what the increased risk is for nurses (and for teachers). On this basis, he corrects the expected levels for nurses by dividing the male expected figure by 0.06 and for females by 0.36. This reduces the number expected for nurses overall from 87 to 20, and raises the PMR to 320. Much higher than 100, suggesting that nurses in the period 1960-80 were at increased risk of asbestos exposure leading to mesothelioma. Howie is currently undertaking further work in this area and aims to publish the results soon.

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Appendix 2 Rapid Review PRISMA chart

PRISMA 2009 Flow Diagram



Appendix 3 Transcripts of two Youtube broadcasts and one blog.

Dr Mags Portman on living with mesothelioma and the importance of research

https://www.youtube.com/watch?v=i_6SGJzh2x4

Hello my name is Mags Portman. I am a mum to two lovely boys, married to Martin and I'm also a medical doctor. Up until my diagnosis I was working in London as a consultant in HIV and sexual health. My area of interest was, and still is, very much HIV prevention. So there is something kind of sadly ironic about me being diagnosed with a preventable cancer in January 2017 in terms of pleural mesothelioma.

Working in the area I couldn't help but draw some parallels between my situation and the situation in the early days of HIV when young people, and yes, I do consider myself still a young person, diagnosed with an incurable illness.

I observed in HIV how investment in research and development of amazing antiretroviral drugs mean that people can now, when diagnosed early enough, start effective antiretroviral therapy and they can live a normal life expectancy and they are not infectious to their sexual partners.

Sadly, even though we know that asbestos-related diseases have been around for longer than HIV there hasn't been the same investment in research and we are really lagging behind. So that's what's really exciting about this new initiative from Mesothelioma UK.

To go back to myself, I had initially a fantastic response to first-line chemotherapy. I completed treatment in May 2017 when there was really very little to see on my TT scan and the disease left. However, very unfortunately, as with pretty much all mesothelioma cases, I had recurrence of disease after only four months. I had some further chemotherapy in December and January which didn't make any difference. The disease continued to progress and I very recently started immunotherapy which I have to pay for and it's really too early to see whether that's making a difference.

One good thing over the course of my treatment has been the knowledge and awareness of the clinical trials that are around; and Mesothelioma UK and the nurses, particularly Liz Darlison, thank you Liz, have really been invaluable in keeping me informed as to what is going on and what's available. And I really do see clinical trials as a glimmer of hope. It would be very, very difficult to – I think – cope without knowing that there's something else available out there even though the benefits at the moment is undetermined. I feel very, very passionate about the value of clinical trials and research; but this needs investment.

So research does change lives and I am constantly heartened by my patients some of whom are long-term survivors who were diagnosed with HIV in the 1980s and are still here today. So even if I can't ride the crest of the wave I hope there are others who can and who will benefit from ongoing research. So thank you everybody.

BLOG: Not doing things by half: Dancing with death and depression

October 5 2018

It has been over six months since I last wrote a blog. The reasons why will become apparent if you read on. My apologies to anyone who has been in touch and I haven't responded, the same reasons apply! Your contact has been much appreciated. I am slowly working through messages and will be in touch.

Let's rewind to May 2018. It was my birthday and I took the above photo on the way out for a family meal at our local and infamous Italian restaurant, Rico's. The problem was, I could hardly eat anything as my abdomen was distended and I felt very full very quickly. I was also extraordinarily tired. The following week was half term and we went away glamping to Norfolk. (A fantastic campsite for anyone interested! www.swallowtailholidays.co.uk) I remained knackered and as a result, struggled to enjoy the holiday. I was also waking up during the night with sweats and chest/back pain, having to take extra oral morphine. Not a good look, eh.

Fast forward to the end of June and the situation had deteriorated significantly. I felt like I was dying.... Probably because I was. The night sweats had become 'all day and night sweats', the tiredness had become an inability to get off the sofa unless I really pushed myself, and I fell asleep frequently. I had lost lots of weight and my skin was hanging off me.

There were horrible symptoms too, like an increased gag reflex on taking tablets or cleaning my teeth, sometimes making me vomit. I said to Martin that I felt like I needed someone to look after me, and I was increasingly unable to do simple things like make a meal. I stopped driving as it felt unsafe, and I stopped doing my beloved Pilates classes. I stopped reading as I couldn't concentrate, and I stopped knitting. I stopped using social media. I stopped having a shower and wearing makeup. It is at this point that my in built, lifelong, taken for granted, conviction changed from 'I CAN!!!' to 'I *can't*'. I do have some happy memories of this time though, time spent together with my family, watching World Cup Football!!

Because I felt so awful, I ended up on the Oncology Assessment Unit. My resting pulse rate was around 125, and I had raised inflammatory markers, but wasn't septic. Nothing else was found. The next morning I was back up at the Leeds Cancer Centre for radiotherapy, which had been started because of the pain. Following this I was meeting a friend Vicky, with a history of cancer herself. You can see her blog here. www.carryoncancer.blogspot.com. On meeting her, I just burst into tears, explaining how awful I felt. Thankfully for me, she took control which was exactly what I needed!! She turned around and took me back up to the hospital, back to the Assessment Unit.

This time, I had a CT scan (thank you again Alison Young) the results of which were enormously scary. Significant disease progression of the right sided disease. Mediastinal disease. Peritoneal disease. Metastasis in my left lung. Enlarged lymph nodes everywhere. No wonder I felt so bloody awful!! I had an appointment with my consultant the next day. Obviously, the immunotherapy wasn't working and we needed a new plan. The only option was to switch to further platinum based chemotherapy. I was told that there was only a 10% chance that this could help, and there was a similar chance that it could make the situation worse (i.e kill me). The likelihood was that it wouldn't really change things. Having no further treatment was also something we discussed. With the way I was feeling, I could have taken this option, but my determination, albeit flagging determination, kicked in, supported by a 'let's do this' attitude from Martin.

I started chemotherapy with carboplatin and gemcitabine two days later. I had already been referred to the Palliative Care Team at St Gemma's Hospice, and the District Nurses. Quite quickly I felt an improvement. The sweats improved and I was less fatigued. Another problem was developing though. **Anxiety.** It reared its ugly head so quickly. I was taken completely unawares until was right in the middle of its grip, smothered by it. Rendered completely incapable.

The 'I can't' voice in my head persisted, became louder and more repetitive. I would sit and wring my hands, rub my face and head, stand up and then sit down again over and over. Minutes and sometimes longer would pass with me staring into space. I ruminated over ridiculous things. I couldn't sleep. I hated myself and my life, what I had become. An incapable individual. I knew that this was so wrong; I was at the end of my life and should be making the most of the time I had left, but I couldn't.

One morning, after a particularly disturbed night, Martin took one look at me and said 'Ring the GP'. I felt very unsettled by the way he had looked at me and realised that I had to do something urgently. Thankfully, one of the GPs rang back within an hour and was absolutely great with me. He suggested starting medication (which I was glad about and ready to accept). He suggested mirtazepine (which I was glad about too, because it also helps with sleep and appetite, and I was hoping for this). He also referred me to the Young Persons Support Team at St Gemma's Hospice as a lot of my anxiety was around the boys and how we would get through the summer holidays with my deteriorating health. The anxiety symptoms settled within a few weeks and I was so grateful for this.

However, what I didn't anticipate was the depression that followed. I felt like I was staring into a big black hole. Each day seemed to stretch out forever in front of me and I didn't know how I was going to get through it.

Physically I should have been able to do things like make a meal, but mentally I could not. I did not have the motivation. It was as though I needed to retrain my brain to do all of these things. I couldn't understand how I had enjoyed things before, how I had been happy! What did I used to do during the day to pass the time? I still couldn't concentrate enough to read, so just sat there feeling really, really horrible and sorry for myself.

Thankfully things did improve. And I think, luckily for me, fairly quickly. At the end of the summer holiday, we managed to get away to Inverness to stay with Martin's parents. The combination of time with my family, time on the beach and being 'a bit looked after', worked wonders. By the time we arrived home, I was feeling much better. I have now completed five cycles of chemotherapy and despite some niggling concerns, I am vastly improved as far as the mesothelioma goes. I had a scan after cycle three which confirmed that there had been shrinkage of tumours. Hallelujah. Mentally, I am almost back to 'normal', but have lost so much confidence. I can't imagine doing things like getting on a train to London by myself, something that used to be part and parcel of my everyday life.

What I haven't mentioned is that whilst all this was going on, we were having an extension built on the back of the house. I know that this didn't help the situation!! So, here I am. At one point I thought I would never be able to write a blog again, so it's quite a big deal to me that I have managed it. Looking ahead with hope again.

All being well I will complete cycle six of chemo and I'm already looking at clinical trials (again). I am excited to think that I will probably see the boys' birthdays in December and hopefully another Christmas!! Grateful for our NHS and for having been given another gift of life.

This blog is dedicated to Team Portman. Goodness!! I feel so emotional thinking of how you supported me and the family at this difficult time, and continue to do so. Thank you for the child care, the meals on wheels, the cups of tea, the supportive texts, being a listening ear, just letting me spend time with you when I needed to get out of the house. Thank you Jacquie Butterworth for masterminding the Team Portman calendar (not to mention being an all round star). Extra special thanks go to Anna Crossley for organising the meals on wheels, but in particular for seeing me through some of my darkest days. Without you babe, not sure what state I'd be in. Thank you.

Tea and sympathy April 23 2018

I've spoken a lot about how it feels emotionally to live with mesothelioma, but I've not talked about the physical symptoms much recently. Probably because I was trying to ignore them away!! So here goes.

Following the vinorelbine chemotherapy in January, I had a lot of pain at the tumour sites, particularly at the lower third of my ribs (ribs come down a long way at the back I was reminded!). This pain also seemed to radiate forward into my abdomen, but I thought little of it, and it seemed to settle. Associated with the pain was some generalised swelling over my ribs, which I put down to 'inflammation' associated with the chemo. It became difficult to feel the 'dips' of my intercostal spaces (in between my ribs). Again, I didn't worry initially. I did start to notice that my abdomen was a little more distended than usual. I put this to the back of my mind, thinking I was a bit 'bunged up' shall we say, but I wasn't really.

Large meals were becoming a problem for me, not because I didn't have the appetite, but because I couldn't fit them in! And the distension got worse. I also realised that I was needing to take painkillers not for chest pain, but abdominal pain. Then there was also this odd swelling on the right side of my belly which made me look as though I had gained weight, and had a spare tyre

on one side only. I think this is fluid in my abdominal wall, as in the morning there are deep imprints in it. Now it is getting better, it is almost gone in the morning but reaccumulates a little as the day goes on. The generalised swelling in my chest wall subsided, but underneath I noticed that my ribs felt knobbly and irregular. I had some lymph nodes above my right collar bone at diagnosis, and these are back with a vengeance. Plus, whilst washing my arm pits, I noted some new lymph nodes there. Darn!!

Self diagnosis (unconfirmed as yet on investigation) : peritoneal disease, rib metastases and new axillary lymphadenopathy. Double darn.

The shortness of breath was creeping back too.... Imagine trying to yawn, but you can't. This is was it's like trying to take a deep breath on the affected side. You just can't quite get your lung to inflate properly. Initially this feels as though you have a belt around half of your chest, but latterly I felt as though I had a rock sitting in my chest at the level of my diaphragm. Even stretching my right arm into the air makes me aware of the meso, as it pulls and feels tight. Weird, weird, weird.

So, I had all these symptoms and had self-diagnosed, thinking I was handling it ok. This is just what happens with Meso, right? I had already braced myself for it. I told my oncologist of my symptoms at my next appointment (three weeks ago now.) He had the heads up regarding a problem already as had seen my CXR, which, despite my symptoms starting before immunotherapy, had shown subtle progression of disease

since starting immunotherapy. My nurse specialist had been invited into the consultation (always a bad sign lol).

We went through the usual consultation routine, and I presented my case to him as though I was a doctor presenting a case on the ward round. I could handle this. I could!!! An examination came next as per medical routine.

But then came the shocker. Even though I knew what was going on in my body, and had known for a good few weeks, to hear someone state things back to you, makes you realise that you are in fact the patient not the doctor, and is still a shock. In the end I wasn't prepared to hear the words 'I'm not happy. I'm not happy at all with the way that things are going.' I couldn't handle it, I couldn't put a brave face on it.

We discussed the fact that subtle signs of progression on my CXR could be signs of well documented 'pseudo- progression' since starting immunotherapy. This is thought to be down to immune cells being recruited into the tumour as the immunotherapy starts to work, but gives the false appearance on imaging of tumour growth. Dr Snee could see the areas of concern on my ribs and thought that I had fluid in my abdomen, likely indicating peritoneal disease. (In fact, I have since had an ultrasound which showed no fluid in my abdomen, hallelujah!!).

I was a bit of a mess after this consultation and was sincerely glad that Chris, my nurse specialist, was there to pick up the pieces. We also managed to locate Martin who handily works in the Bexley Wing. I felt as though once again I was staring death right in the face. Plans for the summer would need to be brought forward in case I wasn't well enough to make it.

Somehow, I made it home and phoned a friend; my lovely friend Jacquie who has been there for me on so many occasions since we met soon after the birth of our first children, ten years ago. It's amazing how sharing a cup of tea and some tears can do wonders. I felt calmer and more able to face whatever the future may hold.

Thank you Jacquie for being there for me. This blog is dedicated to you.

Outstanding contribution award 22 April 2018

This blog is going to be different!!! Mesothelioma is NOT going to be the main focus.... Hallelujah! The beautiful, charismatic city of Edinburgh has been my home over the past few days or so, as I have been attending another fabulous conference; the 4th Joint Conference of the British HIV Association and the British Association for Sexual Health and HIV. Spring also appears to have sprung, bringing out the Princes Street Gardens in all their daffodil glory. I was asked to chair a session around four months ago, how could I say no??!!

Due to the unpredictability of mesothelioma I was admittedly thinking, 'Will I be in any fit state to go by that point?' Let alone chair. So, it was exciting already, even for me to have just made it there! The session went well and was a bonding experience with my co-chairs. Interestingly, the conference opened with a lot of discussion around cancer immunotherapies and their potential role in HIV, particularly PD-1 inhibitors.

You will be able to view the talks online here soon. <http://www.bhiva.org/AnnualConference2018.aspx>

I was awarded an Outstanding Contribution to the speciality, predominantly for my work in PrEP. Wow. Thankfully I had prior knowledge, otherwise I don't think I would have been able to hold it together!! Having had my personality assessed a few times over the course of my career I know that I am a 'yellow', with public recognition meaning a very great deal. (www.general-psychology.knoji.com/which-color-personality-are-you-red-blue-green-or-yellow/)

And wow it was a great deal! And is. I am still on a massive high. Thank you to the people who nominated me, voted for me and those who took the time to say well done. Not often in your life that these things happen. Whoop!!!! (Just in case you didn't know already (!) I had bought a new dress in celebration. That line's for you Chris Ward lol)).

I spoke to so many people and there was a great deal of conversation about my health. People were kindly worried about me repeating myself, but the funny thing was, despite talking (a lot) re Mr Meso, I actually found myself thinking about him much less, feeling more positive and getting some confidence back. And perhaps I feel a little better overall??!!! Certainly amazed that I made it relatively unscathed through three late nights with no daytime naps!!!

So. Feeling a little bereft that the conference is over, but so happy to have been reminded again that I work in an amazing specialty with truly special people; doctors, nurses, healthcare support workers, health advisors, psychologists, pharmacists, physiotherapists, occupational therapists, researchers, long term HIV survivors, peer support workers, those in the community sector, activists, those in the commercial sector and those who I've forgotten (sorry)!! We all work so hard and make our own outstanding contribution, a tribute to kindness in healthcare. I love the NHS!!!! I'm going to spend the weekend gazing at this sticker from @ingridkyoung about her new project looking at the role activism played in the PrEP story (I hope that's correct Ingrid!!!) and spending time with my beautiful family.

The T cell and the butterfly, 7 April 2018

Well. I am at this point much earlier than I anticipated. I had hoped that immunotherapy would be a treatment choice I could keep in the bag for a rainy day..... hoping that that rainy day wouldn't come for a year or two. But with no response to second line chemotherapy, and continuing disease progression I needed to do something whilst I was still well. Although excited by the prospect of immunotherapy, I have also a feeling of reticence, because what if this doesn't work? What next? There really is very little else other than more chemotherapy with a different drug.... with the distinct possibility that it may not work. This is why I have been so interested in the MiST trial <http://www.mesothelioma-research-leicester.com/mist/> (<http://www.mesothelioma-research-leicester.com/mist/>) because as far as I understand it, you can 'roll on' to another treatment arm when you fail one.

But hey ho. The trial isn't open and I can't wait any longer. I can't say I feel entirely comfortable with the way I am accessing this treatment. This is because for mesothelioma, immunotherapy is not yet available on the NHS. Had I played my cards slightly differently, I could have enrolled on the PROMISE trial, a 'cross-over' trial of chemotherapy vs immunotherapy. If you start on chemotherapy, you 'cross-over' to the immunotherapy arm when the disease progresses. This trial has recruited really quickly in the UK and is now closing!!! The CONFIRM trial is still open, but this has a

placebo arm and I wasn't sure about that, having had fairly rapid disease progression. See my previous blog for more discussion on this!!! So, I am paying for my drug treatment.

Luckily for me, Leeds Teaching Hospitals operate what is called 'Additional Private Care', a top up on your NHS care. I don't feel comfortable with this either!!! Not comfortable with this for a number of reasons. The first, obviously because I have to pay. But, there is money left from the crowdfunding that Laura Waters so kindly set up, almost enough to cover enough treatments to see if the drug is working, so that is a good start. There is also the compensation money from the government we always said we would set aside for treatment if needs be.

The second reason is that because I am accessing a drug outside of a clinical trial situation, all my data won't be captured and won't contribute towards others potentially getting access to the drug in the future. How well the drug works, whether it improves my survival, whether I get side effects, whether these are problematic – all of this information will not reach a database. More data is needed because at the moment there is only early data from small studies suggesting a benefit. But my data will not be adding to the body of evidence that may eventually lead to NICE approval for this and similar drugs. It may as well be flushed down the toilet, and I'm not proud of that.

Lastly, I find the concept of private medicine inherently wrong. Why should I be able to access a medicine

in my time of need, just because I can pay, when my friend across the road can't afford to? I don't want to be part of the blurring of boundaries between NHS and private care, the takeover of NHS provision by private companies via the back door since the Health and Social Care Act 2012. But faced with a terminal illness and the accompanying short-term choices, I **am** part of it and I actually feel as though I have no choice.

So. I had my second dose of Pembrolizumab yesterday. It is given as an intravenous infusion over 30 mins every three weeks. Nothing compared with the whole day event when you have standard chemotherapy with Pemetrexed and Cis/Carboplatin! Thankfully, the first time, I had a bit of salt water through the drip to begin with. This meant that when I developed a flushed red face, I knew it was definitely just my old friend anxiety, and not a treatment reaction!!

I had no problem with the actual drug itself and have been completely fine since. Maybe a little bit tired the day after, but no other side effects, and I also seem to be sleeping a bit better at night. Hallelujah! With a treatment such as this though, side effects can occur further into the course, so I'm not guaranteed to be out of the woods forever. It does make me feel quite positive about the treatment so far though, as if the chemo is a crude (but necessary) way of bashing the cancer (and my body at the same time) but immunotherapy is working alongside me and my immune system (I hope). We shall see!!

Digressing slightly, I spontaneously visualised a butterfly the other day, which I'm taking as a good sign. When I saw it, I decided to visualise it removing the mesothelioma cells. I had a feeling that the butterfly was symbolic and it seems that this is true. Mr Google says this *'Butterflies are deep and powerful representations of life. Many cultures associate the butterfly with our souls. The Christian religion sees the butterfly as a symbol of resurrection. Around the world, people view the butterfly as representing endurance, change, hope, and life.'* Let's hope, eh.

For those who want to know more about the immunotherapy I am having, it is a PD-1 inhibitor called Pembrolizumab. It is known as a 'checkpoint inhibitor'. Basically it 'wakes up' part of the immune system which the cancer has managed to evade. It allows our T cells, an immune cell which protects us from disease, to recognise and kill the cancer cells. Sounds great doesn't it. However, the downside is that it doesn't work in everyone. More research is being carried out to find out why. A small trial in mesothelioma (Keynote 028) showed that of 25 patients treated with Pembrolizumab, 20% had shrinkage of tumour and 50% had stable disease. Encouragingly, the responses seem to show more durability (last longer) than the response to chemo, but again, it should be stressed that this is only a small trial and we need more data.

You can see the study results here [http://www.thelancet.com/pdfs/journals/lanonc/PIIS1470-2045\(17\)30169-9.pdf](http://www.thelancet.com/pdfs/journals/lanonc/PIIS1470-2045(17)30169-9.pdf). There is also a good overview of checkpoint inhibitors from Cancer Research UK here <http://www.cancerresearchuk.org/aboutcancer/cancer-in-general/treatment/immunotherapy/types/checkpoint-inhibitors>. I will let you know how I get on.

The Madagascan periwinkle affair, 28 Jan 2018

Well! Where to start with this blog – I've been writing it for well over a month now (probably more like three) and so many things have happened in that time.... Lets start with 2018. I was feeling well (very well, probably because my chemotherapy had been deferred but only after I had taken my steroid premed!) and we had the afternoon pleasure of going to a New Years Eve party at a friend's house. Proper live music, loads of kids, food and everything. As we were leaving the party the kids shouted 'Look, a falling star!!!' In fact it wasn't, but something far more exciting: a green and gold meteor – most incredible!!

Great footage here on Twitter. <https://twitter.com/tomjavens/status/948255670326956032> (<https://twitter.com/tomjavens/status/948255670326956032>)

Surely we will have been brought luck having seen that? My oldest son, very pragmatic, doubts my logic on that one.

On to the train station to pick up my mum, grab some food, then home & putting the clocks forward (!) to celebrate the bells early with the family. We all had a soft drink of something sparkling in champagne glasses. A new way of celebrating, but great to bring in the New Year with all our little family. Martin and I did still stay up until 'proper midnight'... rude not to!!

A lazy New Years Day and then bang! Back to reality. Kids back to school and I started Round two of oral Vinorelbine chemotherapy. Why was I taking Vinorelbine you may ask? Well, after confirmation that the meso was growing again, I took a bit of time to come to terms with things, read over options, and found that I had lots of questions. I knew that immunotherapy was on the cards and would be a good treatment choice. However, I was also interested in joining a clinical trial at some point, and wanted to be sure that I wasn't going to make a decision now, that would prevent me from joining a trial in the future. Supported by the team in Leeds (thank you, and thank you for picking me up again..) Martin and I travelled to Leicester to attend the dedicated mesothelioma clinic there.

The definite 'air of camaraderie' and mutual understanding distracted you from how busy the clinic was (very). I bumped into a fellow #mesowarrior, Linda Lakin, making the whole experience even more of a pleasure. How lovely to sit and chat to someone who can relate directly to my situation, in person and not just online. I was introduced to the clinic by Karen Lord (Clinical Nurse Specialist) and I was seen by Liz Darlison, National Mesothelioma Nurse Consultant. It felt a little odd with me now as a 'proper patient' rather than conference speaker, but also very reassuring to see a friendly face. Liz and her role has been so important to me over the past year.

The reason I had wanted to go to Leicester was to see Professor Dean Fennell, who leads on many of the mesothelioma clinical trials in the UK. We had an incredible quick fire conversation about current and up and coming trials, plus the basic science behind a few theories. I felt like a sponge taking in all this new information, but could only really remember it in layman's terms in the end!!! We didn't decide on a definitive treatment plan, but LOTS of options. Some options that I wasn't aware of previously, so it was definitely the right thing to go. One option I hadn't previously considered was the 'VIM' trial. This was what had been suggested for me by the Leicester MDT.

Martin and I quickly googled it and I realised that it was basically a placebo controlled trial of Vinorelbine vs active symptom control. The patient in me felt very strongly that I wasn't interested in a trial where there was

no option of getting an active drug at this stage of my treatment journey. I was worried by the speed at which my symptoms had returned and were progressing. I don't want my kids to lose their mum sooner than they have to. It is interesting to reflect on this gut reaction now, because on the journey home, my steadfast opinion started to waver, as the doctor in me started to talk.... Why not do the VIM trial? I wasn't that unwell and I could probably manage a few months off treatment if I was randomised to active symptom control and not chemotherapy. I knew though, that further down the road, when options are running out, any clinical trial, placebo controlled or not, is a far better option than nothing. The doctor and researcher in me felt quite frustrated and embarrassed by the patient in me. I felt in quite an ethical conundrum.

Having worked in HIV I knew that none of the advancements would have been made without people, patients, YOU! taking part in treatment trials.

We simply would not be where we are today with HIV still incurable, but a manageable disease with normal life expectancy when diagnosed and treated early enough. A good few weeks have passed since this appointment and it is interesting to look back on my assessment of the situation then. I realise in retrospect, that my knee jerk opinion of the VIM trial, was in fact flawed. Sometimes, active symptom control may give a better outcome than an 'active drug' if the 'active drug' doesn't work, and gives side effects. We live and learn!!!

After considering the options suggested in Leicester, I concluded that I wanted to aim for a Phase II clinical trial. This is more about dosing and safety than how well a treatment works, and may carry more risk. But, it can occasionally offer greater benefit than routine care (although absolutely not guaranteed). When you are living with an incurable illness, I guess your attitude to risk changes. Interestingly, I wasn't up for much risk when initially diagnosed, including accepting the 1% risk of death with chemotherapy! On reflection, I think that is because I hadn't accepted my illness and was in extreme denial. Now, I feel differently, but also want to take calculated risks with the possibility of maximum benefit (if that is indeed possible lol.....and I guess with that comes the possibility of more disappointment too..).

There are lots of exciting trial options open already for mesothelioma, and more coming through. If you want to find out more about clinical trials for mesothelioma, then Mesothelioma UK has a very useful page just here <http://www.mesothelioma.uk.com/information-and-support/clinical-trials/> (<http://www.mesothelioma.uk.com/information-and-support/clinical-trials/>) So!!! The issue then was to stay well enough to enroll in a trial in 2018.

Considering all discussions with Prof Fennell, I felt interested in oral chemotherapy with vinorelbine as a holding measure, hopefully keeping the meso at bay, and me well enough for a trial. Which brings me to my love-hate relationship with Vinorelbine! Vinorelbine is a vinca alkaloid chemotherapy, derived from the Madagascan Periwinkle. This appealed to the plant lover in me :). The little pink tablets just look so sweet and innocent, and admittedly, not having to have intravenous chemo or be on the chemo ward for 12 hours at a time is a HUGE BONUS. This, however, lulled me into a false sense of security. I kinda didn't really feel as though I was taking chemotherapy, just pretending. But hey presto, the little periwinkles decided to make themselves known!

You take Vinorelbine on day 1, day 8, have a rest on day 15 and so it becomes a three weekly cycle. The most common side effects are as with any chemotherapy, nausea/vomiting, diarrhoea, hair thinning, neutropaenia (low white cell/neutrophil count)... I had none of these. On the first cycle I had chills, and then a fever, 48 hours after the Day 1 dose. My rock of a friend Jackie took me up to the assessment unit at 10.30 pm. I was convinced it was a drug reaction as I was otherwise completely well. I had raised inflammatory markers in my blood, my white cell count was mildly raised but not neutropaenic, so thankfully I was allowed to leave the ward at 2am – it was little Freddie's 7th birthday and I HAD to be there for breakfast!!

Following the fever I then got intense pain at the tumour sites which I could just about manage with the painkillers I had at home. Felt a bit flaky and slightly reticent about the second dose, but was reassured by a lovely registrar, and went on to have dose two. I had by now read the Vinorelbine Summary of Product Characteristics in depth and realised that fever and increased tumour pain were possible side effects. The fever happened again after dose 2. 48-72h later, my temperature was 39.6!!!! Again, no other symptoms. Back up to the assessment unit, thankfully discharged later that day, told a viral infection, but I still remain convinced it was the periwinkles at work. Perhaps putting my theory off kilter slightly is that I had another fever a week later. Again no other symptoms, but this time I was admitted overnight..... Ew.

No sleep that night at all. On that occasion I was discharged with antibiotics. I decided to take them, even if only to try to avoid another hospital admission.

On to cycle two!! No fevers so far!! But the intense tumour pain experienced previously appeared again on Day4 and was multiplied by x500. *At least*. Now, I do have quite a high pain threshold, and managed to give birth to my kids with 'gas and air' only, but this pain was *something else*. I had maxed out on all the possible analgesia combinations I had at home, plus the additional Naproxen my GP had given me that day. It was 10pm and I was still in excruciating pain. Still, I decided to go to bed with a cushion wrapped round my chest,

and remarkably actually got some sleep. *How, I don't know, but thank goodness*. Over the next two days the pain subsided, so much so I was pain free off all analgesia, ready to take dose two!!!

And yes, the fever recurred at the same cyclical time point following dose two. Fascinating from a medical point of view, perhaps less so as a patient... Initially I told myself that the fevers and pain were due to an inflammatory reaction at the tumour sites and this of course would mean that the Vinorelbine was working.... But, it was very difficult to work out where the side effects ended and cancer symptoms started.

Over the past few weeks I became increasingly convinced of disease progression, as my cough was getting worse, and I was having more difficulty in maintaining my weight.... I also convinced myself that there was disease in my left lung as I was getting stabbing pains there.... So!!! Following a routine CT scan I was due to speak to Dr Snee this week. I had already convinced myself that he would ring and ask me to attend clinic instead because I sensed bad news.. and he did. As my granny always used to say 'I could write these things'.

'Scanxiety' kicked in and by the time I got to the appointment, I had convinced myself that not only had I got disease progression and new disease in my left lung, I had disease in my abdomen and early SVCO*. So, when Dr Snee told me only of disease progression on the meso side, and nothing else, I kind of did a little dance!! So, not a great situation to be in, but not as bad as things perhaps could be. *Superior Vena Cava Obstruction – this happens when the superior vena cava, a big blood vessel in the chest, is compressed by tumour or lymph nodes. As a result, the blood cannot flow back properly from the upper body to the heart and as a result you get symptoms such as swelling in the face, neck, arms, hands and veins on your chest. I had noted that I had slight swelling around my eyes, probably because I was bloody knackered, not because of SVCO lol....

So. Sadly, the Madagascan Periwinkle didn't work its magic on me, but thankfully, *oh thankfully*, there are other treatment options and trials available. But that doesn't stop the nearness of death feeling that little bit nearer. Fingers crossed I will still make it onto a clinical trial and a miracle will happen. There is still hope. Always hope!!! More info to come over the next few weeks as my treatment plan is decided upon.... Finally, I couldn't let this blog go by without noting that is that it is now over a year since I was diagnosed with pleural mesothelioma. So I have surpassed the 'One Year Survivor' mark.

Not quite as gracefully as I would have hoped given that I have already completed two treatment cycles, but still something to be celebrated.

This blog is dedicated to all the doctors, nurses, healthcare support workers, housekeepers, radiographers, porters and other hospital staff I have met along the way. You have provided me with excellent compassionate care, lots of cups of tea, and it really makes a difference. You are all amazing. Thank you.

The Jack in the box in the corner, 15 November 2017

During a consultation over the summer, when I was enthusiastically feeling very well, and explaining how I was just going to get on with my life as though the cancer had gone, (oh how very naive...) he very pragmatically said, 'But it will still be waiting there in the corner, like a Jack in the Box, ready to pop up at any time'. Indeed, all of us with cancer, and their loved ones, know that this is true. We all carry around our Jack in the Boxes hoping that they won't pop up, but with mesothelioma, predictably they always do. I thought that I would have a little bit longer before mine popped up again, as I was doing so well and had responded so well to treatment. But no, it wasn't to be. It looks like my mesothelioma is just as enthusiastic and energetic as the real me.

It wasn't prepared to lie down on the sofa for long. When I posted 'Back on My Bike', I alluded to the fact that I had daredn't 'go public' with my good news. I realise now, this was partly because I didn't want to face the inevitability of having to write this post. I had suspected that things weren't right for a few weeks and tried to tell myself it was a cold etc etc. Interestingly, all the bad pain I wrote about in 'Little Miss P' has disappeared (I think it was muscular after all..), only to be replaced by intermittent Mr Meso pain in all the classic sites... The cough is back, and deteriorating, and I've also started with night sweats and that fuzzy lethargic feeling.... so all in all, pretty grim.

A chest xray and CT both show disease progression, i.e. that the mesothelioma is growing again. It's not as bad as it was when I was diagnosed, but it has grown fairly rapidly, given that my scan on the 1 September was almost clear. I thought I'd be back at work soon, stepping back into the chaos and joy of a sexual health clinic, but no, I'm again working out the next steps in terms of mesothelioma treatment... This time round I am not so overwhelmed and incapacitated by anxiety, so that at least makes it easier to think and make decisions. But I am sad. Very sad. And when I think about Martin and the kids, I am utterly heartbroken. I am utterly heartbroken.

I wrote those words a few weeks ago and since then the tap of tears has turned down to a drip... I'm still sitting in the limbo land between disease progression and treatment, but this should be sorted fairly soon. Managing to do everything.... but feeling like a stunned animal wading through treacle a lot of the time. For the clinicians out there, I think my affect is fairly blunted!! But I will continue to pick myself up... We will continue as a family to pick ourselves up and get on, because what else can you do

Love hope and rainbow ninjas Oct 13 2017

I wrote this blog post back in May, but didn't get round to publishing, as it was never quite finished and always quite rambling (still is....)!! It relates to experiences in February 2017. In the blog, I refer to a conference in October – well – that is where I am just now!! The Mesothelioma Patient and Carer Day, organised by Mesothelioma UK. The reason I originally wrote this post was to say Thank You to all of you who have provided me with overwhelming love and support over the past months. That still stands. YOU have made this experience much easier, given me reasons to hope, and to live. Thank you.

Here goes. Home after the VATs procedure and I was feeling good. Better than I had done for ages. I had got through the anaesthetic, VAT surgery and post operative chest drain... any remaining pain was quite manageable. Slight bump in the road in that I was allergic to the dressings and their removal was just like peeling off a layer of skin.... Nice!! Allergies certainly notching up... And there were more to come. I had posted my first blog and had 'come out' to the world about my diagnosis. The response was incredible. I am still completely overawed by all the people who took the time to get in touch, write cards, send presents (such thoughtful presents too – you know me so well!!!!). It makes such a huge difference to know that there are people out there rooting for you. If I (still) haven't responded to everyone in person – please accept my apologies.

It got me thinking about love and its importance in day-to-day life. I tend to be fairly liberal in giving love. In the main, this has been a totally rewarding approach to have; not something I consciously chose either. It reflects my upbringing where I was taught it's ok to love and respect, plus I was given the skills to feel confident in doing so. This approach in the workplace has been particularly rewarding. I really believe that if we work towards love and respect across the hierarchy, acknowledging that everyone's role is of equal importance, then we can definitely achieve more together. I digress. Having a cancer diagnosis meant that people were suddenly being so open about their love and respect for me. It was and is, a truly humbling experience.

*We must endeavour to do this for each other **more**, cancer diagnosis or not. I challenge you to tell someone today, why you love and respect them.*

The other outcome of posting the first blog was that because I used the #mesothelioma, I was 'found' by Mavis Nye. I would like to call her 'Mesothelioma Patient Advocate Extraordinaire'. She contacted me to say hello, to see how I was doing, and link me into her Facebook Groups. She was in contact with me a lot over those first few weeks to offer support. And what a difference it made. Peer support was something that was lacking when I was initially diagnosed, but from Mavis' contact the whole mesothelioma community opened up for me.

I was suddenly able to see that I wasn't completely alone, that there were other 'young people' out there, and other women. I also found hope.

Mavis linked me in with Liz Darlison, Mesothelioma Nurse Consultant, who invited me to speak at a conference in October. Bearing in mind that this was only February, I was rather incredulous that she had faith that I would not be dead by then!!! If she believed I would be alive in October, and be well enough to speak at a conference (those of you who know me, know that this is something I particularly enjoy).... Then I could, and would, and DO believe it to.

So, this got me thinking about hope and how very very important it is. Nowhere along the lines had I been given any real reason to hope about the future, other than a discussion that immunotherapies seemed to be coming through and were offering an amazing response in some individuals. Also, there was a recognition that I was 'me', by Mr Papagiannopoulos. (I would like to point out here that 'the future' when you have been diagnosed with mesothelioma takes on a very different meaning. We are grateful for every single day, week and month that goes by. Thinking and hoping about the future does generally not mean 20 years down the line... I wish it did!!)

As we all know by now, mesothelioma is an incurable illness with devastating statistics, but I felt very strongly that I would be one of the 43% alive at one year. I was a young person, still functioning pretty much normally, well... as normally as possible, with a new diagnosis of meso. I looked into the statistics a bit further and found that as a 42y old female, I was pretty much one in a million. http://www.cancerresearchuk.org/sites/default/files/cstream-node/cases_crude_mesotheli_I14.xls (http://www.cancerresearchuk.org/sites/default/files/cstream-node/cases_crude_mesotheli_I14.xls)

Nice huh. In some data from the US, I also noted that survival is longer in young people and in women. I offered this up to my oncologist, hoping to have a chat about his thoughts on prognosis, but no. He didn't take the bait. (Not at that point anyway – we have since discussed this in a little more detail.)

I was interested to read in the book 'When Breath Becomes Air', written by a young doctor, Paul Kalanithi, who ultimately dies of lung cancer, that he often pressed his oncologist to discuss 'Kaplan Meier survival curves'. She was very reluctant to do this to begin with. Understandably, clinicians are often very guarded in discussing prognosis in cancer patients, because it can be so variable. I know this having been on the 'otherside' as a clinician, it can be very challenging to maintain realism, but at the same time trying to support the patient.

However! Now as a patient.... I really wanted to see hope. *I wanted to be given permission to determine to be in the 43%.* (As I write this nine months later, I wonder why I needed permission – I had made the decision anyway.....!) Around the same time a friend of mine contacted me and asked if she could send me a book called 'Love, Medicine and Miracles' written by Bernie S. Siegel, a surgeon in the US who set up the first group for Exceptional Cancer Patients. In this book he writes about hope, including what interested me, the concept of 'false hope'. He says *'...we adopted as our motto a sentence from the Simontons book: **In the face of uncertainty there is nothing wrong with hope.***

Some doctors have advised patients to stay away from me, so as not to build up 'false hope'. I say that in dealing with illness, there is no such thing in a patient's mind. Hope is not statistical. It is physiological! The concepts of false hope and detached concern need to be discarded from the medical vocabulary. They are destructive for both doctor and patient. Whenever I work with medical students or other physicians, I ask them for a definition of false hope. They always hem and haw, and fail to come up with one. I make it clear to them that for most physicians, 'giving false hope' simply means telling a patient that they don't have to behave like a statistic. If nine out of ten people with a certain disease are expected to die of it, supposedly you're spreading 'false hope' unless you tell all ten they'll probably die. Instead, I say each person could be the one who survives, because all hope is real in a patient's mind.

I completely agree with this approach, but realise that it may need to be moderated a little depending upon where a patient is on their journey. Clinicians are actually quite good at assessing when a person is near the end of their life, but what we are not always good at, is acknowledging it, accepting it and communicating it to the patient and their loved ones. Hope does need to be tempered with reality, sometimes. On a personal level, I have always had a particularly high level of determination. To me, being given hope was a reason for my determination and survival instinct to kick in. Hoping, believing, that I will be a survivor at one year.... surely this will only do good?

The reason my friend was moved to send me the book mentioned above, was because I had divulged to her that I had been visualising Rainbow Lego Ninjas removing my tumours. I know this may sound completely crazy, like completely crazy, and of course there is no way I would ever consider giving up tried and tested, evidence based medicine, for visualisation, but I was interested to read about Bernie Siegel's experience working with visualisation in cancer patients. I didn't consciously choose to do visualisations (although I did know something about the concept), they kind of came to me. I had been doing some basic Pilates at home, and was in a kind of 'relaxed zone', thinking about my tumours. This was after the first cycle of chemo and I already felt some improvement in lung symptoms, so was feeling positive.

I guess I had an advantage, as I could visualise *for real* what my lung looked like, having completed anatomy dissection as a medical student. As I was looking at my lung, and pleura, a 'Lego Ninja' appeared, next to some tumours, in fact two Lego Ninjas. One was definitely the leader and she removed her blue helmet, swishing her hair in the same way as Wyldstyle does in the Lego Movie. In fact, she had a similar appearance to Wyldstyle, apart from the fact that she had a blue Ninja mask and was wearing rainbow dungarees (of course). She said "Lets Do This!!" and showed me how she was destroying the tumours. I asked her to concentrate on the mediastinal disease, as this was the part that was worrying me most at the time.

It made me giggle: I couldn't quite believe what was happening....! However, I decided not to worry about my state of mind, but to make use of the fact that these Ninjas had appeared to me, and focus upon them. I decided to devote some time to visualisation every day...more than anything, because it helped me to regain some sense of control.

At the beginning, I saw a lot of them, and it was quite a treat to see how imaginative they were with their power tools!!! They ranged from circular saws (yes ouch), lawn mowers, tractors, bows and arrows, speedboats, abseiling down a bit near my diaphragm using a sword and more. The removed tumours turned into rainbow glitter dust. The second ninja seemed to help with the 'clean up operations' and would pull out any remaining meso cells with a degree of precision, then polish things up

when all the cells had been removed. When I last looked, they had also applied a green transparent coating to the areas where the meso was, to prevent it from coming back. (More recently, the Ninjas have been sitting in deckchairs next to, or swimming in a most beautiful deep blue/green lake containing shimmering fish of every colour...) Remarkable, what can go off in your head (and therefore body) if you just sit back, relax and let your mind do the work!!!!

Or maybe I am just crazy....

This post is dedicated to Mavis Nye – for giving me, and hundreds of other mesowarriors and their families, hope and support. Mavis has recently set up the Mavis Nye Foundation to raise money to further support patients, mesothelioma research and the medical community. <http://www.mavisnyefoundation.com/>

It is possible to donate through the site too, if you feel moved to

Little Miss P, 7 Oct 2017

Pain, it seems, is a fairly expected part of the human condition, especially as we get older. But living with a chronic disease, pain can often go hand in hand with her sister – paranoia. Paranoia that things are getting worse. These two sisters together can shake even the strongest persons resolve.

I guess I have lived with pain now for over two years. It has been variable, therefore easy to brush under the carpet and ignore. For many months I thought that the pain in my back was 'musculoskeletal' and put it down to my lifestyle. It always went

away (or so I thought), so was easy to ignore.... up until my diagnosis of mesothelioma. Then it was as though the light had been switched on and all these unexplained, disregarded pains made sense. In a way, that was good, because I no longer thought I was 'just getting old', or going mad (!) but.... the persisting presence of pain also serves as a reminder of the Big M. Pain is a complex thing.

When I first returned to pilates, and started the first step in putting myself back together again, with the help of most awesome Claire Sparrow, I had a subtle scoliosis, meaning that my spine was bent in a 'C' shape over to the right where the meso was. The meso was causing pain, simply by its presence, and I was recovering from VATs surgery which also had caused pain. These issues resulted in scoliosis; often the bodies protective mechanism. But scoliosis itself can worsen pain, by knocking all the muscles out of line and/or causing them to tighten. As we all know, when pain makes itself known, our brain reacts with an increased awareness, causing the pain to become more noticeable. A never-ending cycle.

Since the success of the chemotherapy, my pain had improved, in fact, settled to almost nothing.... but not completely gone. So, having seen my CT scan with virtually nothing on it, I decided that any remaining pain had to be related to things other than the mesothelioma. And I decided to do something more about it.... Sigh..... In retrospect, I was already doing something about it, but the 'pre-Meso me' had started to resurface and wanted to push myself for an immediate and total solution...

If you read my last blog, you will know that last week was a good week and I felt fairly invincible. How on earth that is possible with a diagnosis like meso I don't know, but there we have it I had many months ago decided to get on with my life, but last week I decided to ramp it up a bit. My aim was to eliminate the chronic intermittent low level pain, so I could also eliminate the reminder of my diagnosis. Oh, it sounds so beautifully simple doesn't it. So. I had the most amazing massage of my life. As you know, I got back on my bike. Lots. I had tinkered a bit with yoga and loved it, so I decided to make it part of my daily life. As a result, I stretched bits that hadn't moved in years. I moved a bit of furniture around, because, well, I could do anything. And guess what. It's not hard is it? You're right, the pain got worse. Quite a lot worse. So, in skips Little Miss P.

Paranoia.

Immediately, I'm back staring into the abyss that is the end of my life. Even though my rational mind is

telling me that this pain is unlikely to be anything serious, and I have just overdone things, little Miss P just won't let up. 'You thought your pain wasn't serious before, and you turned out to have mesothelioma! Hahahahaha!' She's gleefully skipping around my mind, playing her games with me... I know Little Miss P quite well by now. She's all about knocking your confidence when you thought you had it back. She's the one who always spoils the fun at the party. But I am learning how to get her sorted. It usually involves time and patience, replaying the rational side of the story over and over again, a faithful listening ear or two (thank you), a few long walks and of course Pilates. This experience is also teaching me (again) about being gentle with myself and listening to my body.

Thankfully, I have already learnt that my inner strength will eventually reboot itself. After having been through so much over the past 10 months, I really can't expect to suddenly be seventeen again. If you think I ever need reminding of this, please be bold and 'get me telt', I will love and respect you all the more for it!! And Little Miss P. It's time for you to get on yer bike.

Back on my bike 27 Sept 2017

Firstly an apology, this update is well overdue. It is a real time post and will be brief, just to fill you in on important news. I also apologise if you have been in touch and I have failed to return your call, text or message. Thank you for being in touch. The summer has been spent with my head down, pretty much

switched off from social media and spending lots of time with my beautiful family, in some of my favourite places....

Well. Where to start. The biggest news is that I AM IN REMISSION. Yes, that's right.... In remission from mesothelioma. I didn't think that both words would ever go together in the same sentence, but there we go. I am one of the lucky ones. The very lucky ones. Not only am I in the lucky third of people who show improvement following chemotherapy, I have pretty much had a complete response. I literally owe my life to the wonders of medical science and the NHS, to my wonderful oncologist and the incredible, patient nurses who looked after me. Not forgetting the pharmacists who also do an amazing job - respect!

Unfortunately though, remission does not mean cure. It simply means that the cancer has 'gone for a bit of a lie down', a bit of a rest. As I am constantly reminded when reading anything to do with mesothelioma, it always comes back. The big question is when.

I've known about the remission for a few months, but firstly didn't want to share with the big wide world because I daren't actually believe it. It was only after the third appointment with my oncologist when we looked at the scan again, I began to think, okaaaay, this is real'...Recently I've felt reluctance to share because it just feels a bit weird. Don't get me wrong, good weird, but I can't help thinking of all the other mesowarriers who don't have such good news. And a total mind **** to think that six months ago I was preparing for the very real possibility of disease progression and death, whereas now, I'm looking to the future, excited about life and all the new things there are to do!!! Constant readjustment is the name of the game..... and I realise it will be for the rest of my life, for both me and my family.

So, my follow up CT scan a few weeks ago was better than the previous scan which 'won't get any better than this'(!)... I kinda knew, because it feels as though my right lung can now hold more air than the left (this is the case in 'normal people' as the heart gets in the way on the left and the lung is smaller), and the mesothelioma pains have all but gone. Quite mind- bogglingly remarkable. Particularly as I'd not had any treatment for months. Oh goodness, it could have been so much worse. I have to remain plugged in to reality though. For fear of repeating myself, who knows how long this will last for.....? It could be only a few more months before things start to deteriorate, as this is the usual time frame for disease progression.

But! Because I have had such a good response, it could be years.

I have chosen to believe that the mesothelioma has gone and get on with as normal a life as possible. Why wallow in the worry that it will come back? Of course, deep down I know that it will, but I certainly don't want to darken my remaining days, months, and hopefully years, thinking about it if I don't have to. Plenty of time for that, eh. 'Normal life' is nowhere near what used to be normal though; it is viewed from a very different perspective. It is as though I have sped up towards older age and am learning the insight and contentment that older people seem to have... I also have a bit more patience.... yes, really! And, I think I have slowed down.... just a little...! I am blessed to have such a beautiful family that I love so dearly and I spend time marvelling at them everyday. I also think that for the first time, I am really happy in my own skin. I want to look after my body, heart and soul, and it brings me joy to know that I can do this. Since I have been unwell, I've been mostly walking, and using the car for longer trips. But this was starting to annoy me, as I used to cycle everywhere!

So, I just decided, that was it. No more car journeys. This week I have been back on my bike.... And so far I have done it. And what is more, I'm really enjoying it. Even the hills. In fact, especially the hills lol... Down with cars, up with bikes!!! It may sound odd, but I am grateful for the gift of terminal illness and the new eyes it has given me.

Every day I remember though, that I have been given an even bigger gift; that of a little bit more life. And for that I am truly grateful.

Who am I anyway? Part 1: The bus pass, 11 July 2017

Since the VATS biopsy result confirmed pleural mesothelioma (February 2017) we had been getting increasing amounts of post. That day, another official looking brown envelope arrived. I decided to open that one first. Inside was a bus pass. A free bus pass bearing my photo. Quite an old photo; one taken when I still had the red stripe in my hair.

I didn't know whether to laugh or cry. I decided to laugh... The date of expiry was Feb 2020. At least someone thought I would live that long!!! I recalled friends and family reaching retirement age; they also seemed to find issue of The Bus Pass quite a 'momentous occasion'. A rite of passage. Now I could join their ranks, but I was only 42... and mine was a 'Disabled' pass. Highly unlikely I'll ever be granted the 'Senior' version. My bus pass could join the list of other things that come your way when you have a #MesotheliomaCard. If we had a mantelpiece, I could display the pass there, along with with my Blue Disability Badge and the letters concerning benefits I was entitled to... When you have mesothelioma, you have a legal entitlement to certain benefits.... and often they are fast-tracked because of the dire predicament we find ourselves in. But oh the guilt!!!

Being someone with a huge work ethic, and with a stoic Yorkshire personality, I found all this extremely difficult to handle, particularly as I thought I was still well at this point. But the possibility was, that my

health would deteriorate, and items such as the disability badge would prove invaluable fairly quickly. The only statistic that sticks in my head is that of the 43%. Only 43% of people with meso survive a year. It still takes my breath away to write that. Not a good thing when you have mesothelioma!

I didn't even remember that the bus pass had been requested on my behalf, but following confirmation of my diagnosis, Chris, my lovely Clinical Nurse Specialist with support from a Macmillan Welfare Officer, had swooped into action. Amongst other things, they had arranged the bus pass and the blue badge. Amazing. I am very grateful that this had been done on my behalf, because yes, I had bigger things to worry about, one of them being my pride...and probably would have never got round to it. But however grateful I am, I could not get away from the fact that these things all eroded away my sense of self. And their appearance made me feel that everyone thought I was going to die. A DS1500 form was signed by Chris. A usual thing to do when someone has a terminal illness. I nodded agreement throughout this consultation and passively explained to Martin, my husband, what it meant. 'They sign it when you are expected to have six months or less left to live'. 'Just another thing to sort out.' I say pragmatically.

The real me, however, was saying 'WTF This is UTTERLY RIDICULOUS'. Of course I am NOT going to be dead in six months...but then maybe I am. Who knows? That's the nature of this game. Unsurprisingly, as a result of this barrage of developments,

my emotions were 'highly variable', shall we say... Sometimes I felt 'Yeah, I can do it!' such as when thinking about recovery from surgery, and the impending chemotherapy, but there were these new feelings creeping in. Feelings of worry, lack of confidence in myself, and stress about the numerous things needed to be sorted out, to make the end of my life easier for others to bear.

There were constant reminders that I had just been given a diagnosis of an incurable disease, and *I didn't know how to deal with that*. I had also noticed that I was increasingly short of breath and fatigued. I was short of breath when walking on the flat. I was short of breath reading my kids their bedtime story. Not that I would ever admit that, EVER. The pain below my right shoulder blade was there constantly and really quite prominent in the evenings – I could never seem to get comfortable. It was getting easier to start believing that I was going to die, and I was scared. This was going to be the biggest challenge of my life. As you probably know by now, I am a medical doctor, a Consultant in Sexual Health and HIV, and work at a sexual health clinic in Central London, Mortimer Market (albeit not since my diagnosis). I balanced this (perhaps not very well) with being a mum to two beautiful, insightful and humorous boys, and wife to my 'long suffering', handsome husband, Martin. I love my family. I love my job.

I've always been someone with a strong sense of self, high self-esteem and self-belief. Perhaps, fairly egotistical (in a nice way I'd like to think...). From being quite young I had often felt as though I didn't quite fit in, probably as a result of moving house a lot as a child, and my parents not being local to Yorkshire. As a result, I had grown quite a thick skin and eventually felt able to be proud to be a bit different. Outwardly, I am quite a confident person and not afraid to speak up. I have a fairly, or should I even say brutally, stubborn determination at times, meaning that I have managed to achieve a lot in life so far.

When I was told of my diagnosis of mesothelioma, I was hit by this overwhelming feeling of not knowing who I was anymore. It was gutwrenching. All the things I had taken for granted; my strength, my health, my fitness, could no longer be relied upon. How would I be able to function as a mum? How could I continue to support my children's physical and emotional needs when my health was failing, and I was an emotional wreck? Could I ever go back to work? Would this be in the same capacity? At times I really felt that I was no longer the person I used to be. The easy familiarity with who I was had gone, to be replaced by an indecisive, severely anxious person, an observer rather than an innovator. It was going to be a momentous effort to gather up the fragments of my remaining self, and rebuild.

In case you were wondering, I use the bus pass, and I plan to out-live it's date of expiry.

Older Posts Report

The VATS, 26 June 2017

It was a Monday morning 7am, February. I think that my mum was here to look after the kids and get them off to school, but my memory is hazy!!

What I do remember is arriving at the Surgical Ward, which wasn't yet open. As a result there were around 30 patients, most with companions, queuing outside the door. Everyone with their suitcases... It reminded me of an airport, except no one was drinking beer...and it was quiet!!! No cackling hen parties to disturb us...A really odd feeling of waiting...subdued tones...anxious about what was to happen next...

Eventually a nurse came and opened the door, but the wait still wasn't over. She called the names of around half of us...and then asked those people to wait outside the ward! I was one of the lucky ones, allowed into the ward, meaning it was more likely that our surgery would proceed as planned. Hallelujah!!!!

Martin and I sat down next to my allocated trolley, upon which lay a hospital gown, TED stockings, and very glamorous paper pants. I asked for a smaller pair as just looking at them, I realised that there was quite a high chance of them falling off!!! *Unusually* for me, I suddenly didn't fancy being completely on show. Obs done.

Blood pressure a bit high. Told this was 'forgiven' as everyone usually nervous prior to surgery... And then waiting. The realisation that patient confidentiality really is a misnomer in an open ward. It is possible to hear *everything* that is said to the patient in the next bed space.... Oh! A visit from the anaesthetist. I was encouraged as he wasn't just a 'young thing'. Why on earth should that matter?! How weird it is to be a patient. How your perspective on things change. And a bit more waiting... The Porter arrives!! I hadn't actually got changed into my glam hospital gear as no one had indicated what time the surgery would happen. Oops!!! A little embarrassing they had to wait for me to get changed...

Next time I will know better...

I was wheeled through the hospital on a trolley. Again, a very, very weird turn of events. I knew the hospital well, having worked there as a junior doctor. The incongruity of now travelling flat on my back on a trolley through the corridors, as opposed to walking fast with my ID badge swinging, was really stark. In my 'old life' I was always in a rush. Again, awareness of another perspective, this time literally! And then we were there.

I said goodbye to Martin at the door to the theatre. Very surprisingly, I didn't feel that nervous at this point. Quite how, I have no idea!!!! I think perhaps by this stage, I was fairly resigned to my fate. Lots of checking of my ID and allergies. More checking. Drawing an arrow on the right side of my chest where the mesothelioma was...And then very quickly into the anaesthetic room.

EEK!!! This was going a bit too quickly for me!!! But, I was cheered to see the anaesthetist again, and be spoken to kindly by the operating department practitioner. Then I got told off for trying to assist with cannula insertion by rubbing my hand... Just doing my job lol...

Anaesthetist: 'I'm just about to give you the Fentanyl*. I'll give you a few moments to enjoy it before you go off to sleep'. The room then turned into something out of a cubism painting. Straight lines turned jagged as the Fentanyl began to take effect.

Me: 'I'm not enjoying this AT ALL!!'
Then *nothingness*.

*Fentanyl is a painkiller similar to morphine

And in the blink of an eye, I was waking up! I felt intense pleasure, as though waking up from a really lovely dream. I had no pain. I had no nausea. I felt happy. Perhaps I did like Fentanyl after all.... And then massive relief washed over me.

Not only was I alive (!), but the realisation of why I had been so terrified of surgery, and having this procedure, hit me. My only experience of operating theatres as an adult had been observing or assisting in surgical procedures. My subconscious brain seemed to have assumed that I would be observing my own VATS. It thought that I would have been witnessing the surgery and therefore seeing the tumours all over my lung. Visualising the mesothelioma, the cancer. But I had woken up from surgery without having any recollection of events. I had simply been the patient. Not the assistant or observer. I was *enormously* relieved and thankful. My mood lifted immensely after the VATS; I felt a sense of achievement. I had a beautiful room in the Bexley Wing (so beautiful that I actually shed a tear on arrival) and there were no post-operative complications.

For a change, I was able to be a good patient. I gingerly got up and about, negotiating my chest drain. I ate my food (lots of it). I went for a pee myself (ok, with a bit of help the first time). I had no pain. Then the local anaesthetic wore off. It was around midnight... OKAAAY!!! So the marvels of modern medicine had duped me into thinking that this surgery thing was a doddle... But, I got to grips with my PCA (patient controlled analgesia) and pain settled quickly. The nurses were fabulous. The ward Housekeepers were even more fabulous, keeping me topped up with tea, biscuits and humour. I was on course for chest drain removal and home!!! In the end I was allowed home early – whoopee!!!! Ready for some rest and recuperation, and the next stage in the journey.

Today it is my birthday, 27 May 2017

Ok, so this is a real time post.... It is actually my birthday today. I am 43 years old.

In January of this year I had no idea whether I would still be alive, so this is the first momentous personal milestone for me to reach since my diagnosis of mesothelioma. And it feels AMAZING!

I have a standing joke with my husband that the sun always shines on my birthday.... And it pretty much does. My Dad when he was alive, also used to remind me that as well as the sun, there was a Salvation Army Band playing outside the window of the hospital during my arrival.... thought I'd put that down for posterity too, lol...

So then, how sweet to awake early, with the sun coming through the curtains. And then realise that I had made it to 43!!! I suddenly felt excited!!! I no longer have to care about getting old, wrinkly, chubby, skinny, whatever. The importance is to be alive for a few more precious hours, days, months, and if I dare to dream.... years... The band is still playing...

Because today, I have no symptoms remaining from the mesothelioma. Now I am symptom free, I can look back and see that I had been unwell for a while... Over a year I think.... I had fatigue and hadn't noticed the shortness of breath, as it crept up so slowly. But now, what joy to be able to take a really deep breath in and fill my right lung with air!! Today I cannot feel the niggling chest pain, just below my right shoulder blade, which had reached quite a crescendo before I started chemotherapy. So I am going to enjoy these moments, and ignore as much as possible, the few ill effects from the 5th cycle of chemo I had 2 days ago.

I know that I am one of the lucky ones, the lucky ones who actually respond to chemotherapy. and for that I am immensely grateful. I have been given the gift of life for a little while longer. Who knows how long that will be, but today, I am going to enjoy it.

I have been into the garden already (at 6.30 am!), walked amongst the slugs and snails on the dewy grass in my bare feet, and looked at the vegetable plants growing from the seeds I have planted. I know that it is set to rain later, and it looks like storms (!) but we will deal with them when they come. So to finish, I want to say a MASSIVE THANK YOU to OUR NHS and to all the people who have cared for me and continue to do so. And thank you to all of you, for your ongoing love and support. Here's to making it to 44!! With bells on.

Part 6 significant denial, significant others 24 May 2017

Just a reminder that this blog post relates to February 2017. I've decided that the way I am writing is not great for keeping people updated – apologies for that. I plan to tweet more updates as an experiment and will reassess (whether I can keep it up (!)). I'm @magsportman on Twitter.

Lets jump back to the end of part four of my blog. I'd been given my diagnosis of the Big M. I need to fill you in on a bit of the story.... Writing about the importance of hope will have to wait (again lol).

The next thing to happen was that I was to see a surgeon prior to a surgical VATS procedure, biopsy and talc pleurodesis. <http://www.uhs.nhs.uk/Media/ControlledDocuments/Patientinformation/Heartandlungs/VATSlungbiopsy-patientinformation.pdf>

Unfortunately, my medical brain had gone into overdrive and I wasn't 100% sure about this! Plus there was a wait of 11 days to see the surgeon (ok, so in reality, a completely insignificant wait, I know..), then I anticipated a further time to wait for the actual surgical procedure... More time for my brain to question what was going on!!! Secretly, I was *glad* of the wait too, because this meant more time I could pretend it *wasn't actually happening*.... My lovely friend Dr Laura Waters, who has been so very supportive in many ways, (sending me oodles of my favourite Yorkshire Gold tea, Lego for the boys, texting me almost every morning, and of course setting up the Just Giving page...), swooped into action and helped me to arrange an appointment with a surgeon for a second opinion. She also accompanied me to the appointment – I was, and still am, incredibly grateful. Thank you Laura

The appointment went like this. 'I'm so sorry to hear about your diagnosis. Absolutely devastating for you.' 'I realise that you are here to discuss surgery, well, I need to remind you that all surgical procedures for mesothelioma are purely palliative.' Both myself and Laura, I think, needed a moment to gather ourselves. I was probably sitting there with a bit of an open mouth... The surgeon spoke the truth, but it is quite difficult to be faced with this stark reality so early on in a consultation, when I guess that we had gone to find a bit of hope.

I have thought about this approach a lot, and wonder whether the surgeon was, in addition, expressing his own devastation at seeing yet another person, another colleague, affected by this preventable disease. I also recognise that my reaction was mainly due to me still being in denial of what was happening. (Internally I was horrified – I did *not* want to be reminded that my diagnosis was devastating). Everything was still so new, and I hadn't got used to how I would react to sympathy from others... But! I still think that there are other ways of wording it... There was then a discussion about various surgical options available, from symptom control only, to more radical approaches and the benefits and side effects of each. Eventually, I was advised that a pleurectomy *may* be of benefit and that I didn't necessarily need a VATs procedure prior to proceeding with this. The surgeon was kind, well meaning, and wanted to help. He was very honest with us and explained how his opinions, and therefore approach and advice to us, had been coloured by his experiences over the years. I remain thankful for his opinion, which completely tallied with the way that I was thinking at the time. Despite this, I kind of left feeling like I'd been put through a washing machine on spin cycle, and felt *more* confused as to the best approach. Confusion, and an inability to make a decision seem to be my bed-fellows at the moment... I also needed to take into consideration that any treatment outside of Leeds would potentially be more of a challenge.

My oncology doctor friend randomly contacted me the next morning to see how I was doing and I had to admit to her that I wasn't doing that great... Confused. Worried. Worried. Confused. Scared. Worried. Confused. Unable to think straight. Wishing that I wasn't a doctor and over-analysing everything. She arranged for me to meet my oncologist, Dr Mike Snee, that day. Thank you both for going out of your way to accommodate a slightly crazy, or should I say crazed, doctor-patient.

Dr Snee thankfully had a very pragmatic approach (and didn't say the word palliative – thank goodness). I was encouraged to 'face my demons' and look at my CT scan. Yes, the mesothelioma was scarily obvious, including some disease next to my mediastinum (the part of the thoracic cavity that lies between the lungs, containing the heart, trachea, large blood vessels and oesophagus). We talked about chemotherapy, plus the option of adding an immunotherapeutic agent (Bevacizumab/Avastin) to the basic chemotherapy regimen (Cisplatin plus Pemetrexed), on the basis of data from the MAPS trial [http://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736\(15\)01238-6.pdf](http://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736(15)01238-6.pdf). Bevacizumab is an anti-angiogenesis inhibitor, meaning that it stops the formation of new blood vessels, something that tumours grow in abundance! So, stopping new blood vessel growth, basically means stopping tumour growth too. But, fairly understandably, it also comes with additional side effects. And I would have to pay for the Bevacizumab as it is not yet agreed by NICE....

Chemotherapy sounded like a reasonable plan, a good plan, and I knew that it was the only treatment option with Grade 1 (the best) evidence. But I still felt as though I was going through the motions... Was this really happening? Did I really need chemotherapy? Me? Really? Surely not. I struggled with the need to agree to anything, when I still couldn't quite believe I had cancer. Especially anything which listed 'risk of death' as a possible outcome. How on earth could I have to sign up to this??

I managed to hold it together until the end of the consultation when thankfully Chris, the nurse specialist, who had been present throughout, took myself and Martin off for a cup of tea with a side order of tissues. Thank you Chris for picking up the pieces..... again....

Fortunately, Dr Snee seemed to realise that I needed a bit of direction, and arranged for me to see a surgeon in a few days. That surgeon was Mr Kostas Papagiannopoulos, who also very kindly spent a long time with myself and Martin. He is certainly an empathic surgeon with a twinkle in his eye!! He drew diagrams to explain things to us; that kind of approach really appeals to me. The Art of Medicine, or perhaps I should say Surgery.... He made the analogy that treatment would be like a journey, and that a decision about the next bit of travel would be taken

depending upon response. 'Bumps along the way' were also mentioned; a concept which has borne out as true already. Very true. He had booked me for surgery in three days' time – Monday morning 7am! I agreed, reluctantly... one half of my brain saying 'Just get on with it Mags' and the other saying 'You've still got time to change your mind!'

The illustration used in this post is taken from here <http://www.myspecialks.com/2013/06/denial-not-just-river-in-egypt.html>. This post is dedicated to Dr Laura Waters for being an all round star.

Part 5 – the terrors, 7 April 2017

As some of you are aware, I am writing this in retrospect: This works well in that it gives me time to reflect upon events, and perhaps give additional perspective, but it means that I am not really keeping you informed with what is going on with me! I hope that you don't mind too much... This part is going to be a bit introspective and I think difficult to write, but I want to put down in words the significant psychological challenge that follows the diagnosis of an incurable illness.

You may remember that the first step in my diagnosis was an abnormal chest X-Ray. The knowledge that I had fluid on my lung changed my behaviour immediately, in a negative way. Suddenly, I was no longer confident in my ability to cycle home, and had to have a lift. If I had not known about the X-Ray, I would have just cycled and got on with it. I may have struggled, and wondered why my breathing felt a bit restricted on going uphill, but I would have just got on with it... because that was what I did. My usual state being that of determination and confidence in my ability to succeed. I have no memory of the day after learning of the CXR result. The day following this, I most certainly do remember. I remember it because I had an overwhelming feeling that I was going to die. I was going to die.

I was going to die.

This was the first of a number of events that I now recognise as panic attacks. At the time I thought that whatever was causing the fluid on my lung was progressing.... It had after all, been over a week since the last X-Ray, and I knew that it was possible to deteriorate quickly when you had a pleural effusion.

It was a Saturday and I usually take the kids to their dance class, with a trip to Café 164 as a little treat. This Saturday though, I wasn't sure whether I would manage to take them, as I was going to die. Seems crazy saying this now, but that is how I felt. I courageously asked my other half if he would mind not going on his beloved Saturday Morning Bike Ride to take me and the kids to dance. He eyed me very suspiciously, particularly as I suddenly felt the need to sit down on the kitchen floor, but thankfully he agreed (as well as instructing me rather vigorously to 'get up')! I phoned my best friend, Caroline, who thankfully had already said she was coming to visit. She was driving down from Glasgow. I was panicking that she may not make it in time; that I would have been admitted to hospital before then. Because I was going to die. After an hour or so I began to feel better and could actually have minimal conversation, rather than staring silently at the world, wondering what was going on...

Later, Caroline arrived with her gloriously lovely dog, Sandy, and 'dog therapy' began. It worked a treat. I could feel myself, and the whole family, relax. Who couldn't, in response to his boundless cuddles, curliness, smelliness?? With support, I made it through the weekend, and the feeling that I was going to die lifted. The terror had subsided, for now.

Of course, it returned. And was more severe. I recognise now, that after the initial shock of realising that there was something wrong, anxiety came in waves, worsened by having a test or an appointment, but it was always there.... Part of me. Making me hypervigilant, then increasingly anxious.... and the cycle continued....

Then, on occasion, and taking me completely by surprise, the terror returned. Just like that. One minute I was ok and everything was 'normal' and the next moment, I was going to die. These moments started with a dizzy spell, but then in seconds escalated to heart racing and pacing the room, because if I didn't, I thought I would

collapse and die. These events were completely out of my conscious control. A small part of my brain rationalised that I was having a panic attack, but I still was unable to control what was going on.

This happened the night before I was due to have surgery, a VATS biopsy and talc pleurodesis. There's a great leaflet here <http://www.uhs.nhs.uk/Media/Controlleddocuments/Patientinformation/Heartandlungs/VATSlungbiopsy-patientinformation.pdf> I was sitting on the sofa happily on social media and (as far as I was consciously aware) not really worrying about the impending surgery. But then, suddenly, room spinning and the feeling I was being sucked backwards into unconsciousness. Then terror. I was going to die. *I was going to die. Big time.*

Was I having a dangerous cardiac arrhythmia (irregular heart beat)?? Had the mesothelioma started to invade my heart?? My fingers were white. The sheer panic I felt was reflected in the faces of both my mum and Martin. I phoned a doctor friend, Alison. Rather amazingly, she was on call and calmly, she sorted me out. I'll not go into detail, but thank you. The worst of The Terrors happened two days before I was due to start chemotherapy. I had been feeling quite fatigued... I'm still not sure if this was due to my state of mind, or mesothelioma itself. The 'terror' was so severe that I phoned Martin to come home from work. I could barely sit up from the sofa. I could barely walk. I was literally shaking all over.

I remember gripping the car door handle and urging him to go through the traffic light on amber, in exactly the same fashion as I had when I was about to deliver my second child!! Yes, I went to hospital, because I thought *I was going to die*. I was assessed in the Oncology Assessment Unit at St James Hospital. As soon as I arrived and the nurse did my blood pressure and pulse, I started to weep uncontrollably, gripping onto her hand for dear life. I was alive. I WAS ALIVE!!!! Ok, so I was hypertensive and tachycardic (blood pressure and pulse high), but I was alive. After half an hour or so, I had stopped crying and my blood pressure was back to normal. I started to feel guilty for taking up an assessment bed... I spent time with Chris the nurse specialist and was grateful for having met her earlier in my journey.

The staff on the assessment unit were amazing; incredibly compassionate. They didn't make me feel judged for presenting with a probable mental health issue. They were also reassuringly thorough in their assessment, to ensure that, despite me stating I thought I was having a panic attack, there was nothing else underlying my symptoms. They didn't make me feel like a crazy doctor (which I was starting to feel like..). This was the last of The Terrors to date.

Starting chemotherapy was like being given new life. Although it brings with it its own worries and anxieties, these are nothing like 'the pre-treatment void' which allowed The Terrors to develop. It has given me something positive to focus on, has allowed me to regain some confidence, and with it my sense of stubborn determination and will to live. More on that later.

Part 4 - The big M, 17 March 2017

Only six days after meeting Dr Rodger, we were back again for results.

Before that, I had a further CT scan to look for evidence of a primary cancer in my abdomen or pelvis, plus a brain scan as I'd been having headaches. As I was a seasoned patient by then, I rather bravely swanned into the radiology department on my own, armed with my water bottle to fill my bladder. Despite this scan happening in a different hospital, it happened to be the same technician who took my details and inserted the cannula, along with a bit of banter. All very reassuring and I felt as stress free as one can in these situations. But my calmness was not to last....

Into the scanner. Come on Mags – you can do this! The contrast went in, and worryingly I started coughing. I tried to go back to my 'happy place', this had worked well during the previous scan, but I did not feel right. The radiography assistant came in to check that I was ok, i said yes and the scan continued to my brain. In reality, the scan was over really quickly, but it felt like an age! I wanted it to be over! I could feel myself getting stressed and panicky; I was so glad when it was finished, but I still did not feel ok. I felt all wobbly and could feel my face burning. The radiologist was called; was I having an allergic reaction? I stated that I usually got a rash on

my neck when I was stressed, and I was probably just anxious? The radiologist ASKED ME if he should give me anything for allergy. How would I know? The joy of being a doctor patient. I couldn't see the rash, or my face to aid in the decision-making process. In the end we opted not to, but as I still felt wobbly, I went to the recovery room. I saw my face in the mirror – it was completely flushed, much redder than my usual stress rash.

I laid there, flat on my back on a trolley in recovery, staring at my red boots and wondering about the unreality of the whole situation. Being on the 'other side'.... Oh what was I doing there? After a few more checks by the doctor, and calling on my long suffering husband for support and a hot chocolate, I eventually I felt well enough to go home. I was given a little warning card on 'delayed reactions to CT contrast'. And.. a few hours later, there it was. A widespread rash on my trunk. So, it hadn't just been stress after all. I took some antihistamine, messaged some doctor friends to calm my nerves (you know who you are, thank you), and in the morning the rash had pretty much gone. The whole experience had played havoc with my anxiety levels though!!

Back to the follow up appointment.... Quite straightforward really. The FNA from the glands in my neck was benign (negative) – wahey!!! But, and quite surprising to me as I know that the pick up rate from pleural fluid is quite low, cancer cells had been seen in the fluid. (But then again, maybe not surprising given the ultrasound appearances with the cells floating round, seen even with my untrained eye lol). The cells were of 'epithelioid line', meaning that they originated in epithelium (skin, or tissues that line or cover internal organs), and more detailed tests were needed to tell us exactly what cancer cell type they were. This included the possibility of a spread from a breast cancer, and I was told I needed to have a mammogram. It also still included the possibility of mesothelioma. My husband told me that if mesothelioma was the final diagnosis, he would faint. Great!

I can't say that I actually felt any emotion at this point. Everything felt like a bit of a dream and I was just going through the motions. I had felt so scared and worried over the past few weeks, but determined to face whatever came my way with humility, this was just some more news to deal with. Cancer was the expected diagnosis too... I could see things from a positive perspective; this was the next step towards an actual diagnosis.

I suggested to Dr Rodger that it would be ok to email any other results. She said to me that she would be much more comfortable with a phone call at least, if I wasn't to come back for an appointment. In retrospect, *of course* she was right... I suspect I was just trying to be brave and save the NHS some time!!! She called another six days later as I was stepping off the train at Kings Cross, London, and I missed the call... aaargh!! I was in London to be interviewed for a new film on PrEP (HIV prevention medication), the follow up to the PROUD film called PrEP17. (The link to the PROUD film is here <https://vimeo.com/132412294>)

Thankfully I was meeting a good friend and comrade, Greg Owen. We were planning to go to an event called Sextroverts, but in the end didn't make it... We walked (and ended up going the scenic route as both of us relied on the other to find the way, and neither really knew exactly where we were going, just the vague direction.... I'm sure Greg will disagree with that though lol). I didn't want to go on the Underground as Dr Rodger had said she would call back.

Which she did, and my phone battery went! Was on 17%, but the phone crashed!!! You couldn't write it, honestly. Thank goodness I had written down the number so was able to call back.

So, I received my diagnosis of mesothelioma on Greg's phone. Something oddly comforting about that, as I knew that Greg too had received a life changing diagnosis a year or so earlier.

My initial response was 'Oh, ok, that's fine'. I think it had barely entered my brain, let alone registered. I thought, well, that's good, less likely to metastasise!!!! Goodness. Dr Rodger confirmed the next step would be to have a VATS procedure. This is keyhole surgery using video which they use to get a formal biopsy, drain the fluid, plus do a talc pleurodesis. (A talc pleurodesis is used to stick the lung to the chest wall to prevent reaccumulation of fluid). I would then receive an appointment to see an oncologist with an interest in mesothelioma, Dr Michael Snee. She also suggested I look into the MARS 2 trial which compares standard chemotherapy to standard chemotherapy plus surgery to remove the lung membrane (pleura) and tumour.

<http://www.cancerresearchuk.org/about-cancer/find-a-clinical-trial/a-study-looking-at-surgery-for-mesothelioma-mars-2> I did look it up later that evening, but again, it barely registered with me at that point. For the rest of that evening, we walked around Soho, had a steak (!) and I had a glass of wine (only one or two, surprisingly) and went home relatively early.

Somehow, I managed to be filmed the next day, (thankfully I was amongst friends – bloody love yous..) and interviewed for a potential podcast on HIV by the Naked Scientists. I think was relatively 'myself' on film, but who knows!!! I will find out at the Family and Friends viewing in April before the film goes out for all to see. Watch this space – I'm sure I'll put a link on here.

Then on the train back home to Leeds, and back to reality. Mind whirring... Mesothelioma, mesothelioma, mesothelioma... And how to tell my husband Martin...

Part 3 – one stop shop, 13 March 2017

It was Friday the 13th January 2017. I had my appointment at St James University Hospital, Leeds in the rather beautiful Bexley Wing – the Cancer Centre. The Bexley Wing is like an extremely glamorous hotel. On entering the building, you walk into a huge, light filled Atrium. This is decorated with tree trunks carved into seats, an art or photography exhibition, and a grand piano is often being played: no matter what the tune, it always sounds beautiful but melancholy...

First I met Yvonne, a Healthcare Assistant. I remember her name as she was great at #HelloMyNameIs. Lung function tests showed my lung function was around 2/3 normal and my oxygen saturations (levels) were measured. I said that I didn't want to know the result unless it was 99%..... It was 99%. Phew!

Then Martin and I were greeted by the lovely Dr Kirsty Rodger, Respiratory Consultant. I definitely did well having Dr Rodger as my Consultant – Thank you Dr Rodger for your support. Also in the consultation was Christine Thomas, Lung Cancer Nurse Specialist. A holistic approach from the start – impressive. I didn't realise that it is a national recommendation to have both doctor and nurse specialist present when giving a cancer diagnosis, but it certainly did make a positive difference to our experience. (And has continued to do so). <https://www.nice.org.uk/guidance/cg121/chapter/1-Guidance#communication>

We briefly discussed my CT scan report and went over the usual things: Presenting Complaint, Past Medical History (how weird that ones mind just goes completely blank, I forgot ALL my PMH!!) and Examination. During the examination, I was rabbiting on in my usual way that I would with patients and asking Dr Rodger lots of questions too – some perhaps a bit too personal – sorry!! But I learnt that we had some things in common, including having both trained at the Glasgow University. Dr Rodger also told me she had a sister who worked in ID/HIV in London – I later had a 'eureka moment' that this was likely to be Dr Alison Rodger, chair of the BASHH/BHIVA PrEP guidelines writing group, of which I am a member, so had obviously worked with her and knew her!!!

A small world..... Again bringing home the weird experience of being both doctor and patient.

Then we came to the more detailed serious discussion. The scan suggested cancer. An incurable cancer. The differential diagnosis being metastasis (spread) from another tumour, such as breast cancer or lymphoma, Primary Pleural Adenocarcinoma (which admittedly I had never heard of) or mesothelioma. It seemed as though Dr Rodger was expecting it to be adenocarcinoma, and was talking about tailoring treatment according to what markers were expressed; ALK or EGFR. Again, I had never heard of these!! A lot of learning to do in a completely different field of medicine from that which I was used to!

It may seem strange, but being faced with a terminal diagnosis from the outset, my initial, impulsive, response was that 'I don't want treatment'. In my head, all that I knew was seeing really, REALLY sick patients on the oncology wards when on call as a junior doctor, mainly admitted due to side effects of treatment. What was the point in going through that if I was going to die anyway? I have since learned that only around 3% of people receiving chemotherapy are admitted, so what I knew was a fairly skewed reflection of reality! My gut reaction was that I was well, I could still walk, cycle and that I wanted to 'be myself' and away from hospitals for as long as possible, if death was inevitable. Obviously, *and on reflection thankfully*, I have since changed my mind...

Even though this appointment was hard, I felt a strong sense of relief to share my (as yet unconfirmed) diagnosis with medical professionals. Even though they couldn't live the experience for me, I felt supported and less alone.

We spent some time with Chris, the nurse specialist afterwards. She introduced the idea of lots of issues we had never even thought about. Again, so good, refreshing even (!) to have both a medical and psychosocial nurse consultation at the same time. It made me consider what happens when we see a patient newly diagnosed with HIV in clinic. I was thankful to realise that we have the same holistic approach, including introducing people to patient representatives.

My main concern was for my kids, how to speak to them, what support was available for them? We were given this leaflet and found it extremely useful <http://www.macmillan.org.uk/information-and-support/coping/talking-about-cancer/talking-to-children/advice-on-talking-to-children-about-cancer.html#19687>. It seems that there is support here for older children and teenagers, but for younger children it is mainly via the hospice – and we were certainly not ready for that yet. (Please don't worry about this though – the school has been AMAZING and has bent over backwards to support us all as a family, to them I am greatly indebted – thank you Roundhay School Primary – you're fab).

I wasn't sure when I went along to the appointment if anything else was going to happen that morning, but it did! Like everything happened! A true One Stop Shop. Firstly blood tests, and for the first time, the not so good bit, the waiting room was far too small for the large number of people waiting. About the size of a small toilet!! Perhaps it was just a busy day.

Then onto radiology for a fine needle aspiration (FNA = removal of cells from a lymph node or gland using a needle) of some glands in my neck, plus taking off some of the fluid on my lung, and possibly a biopsy of the pleura. The FNA was far better than I would have thought. Sorry I can't remember the name of the radiology consultant who did this. She was very accomplished with the local anaesthetic and I hardly felt a thing. The local anaesthetic for the possible pleural biopsy was a different matter though – yeowch!!! In the end after removing fluid for testing for infection (including TB) and cytology (looking for cancer cells), my lung expanded and the biopsy was looking a bit more difficult.

At this point I made the mistake of agreeing to look at the ultrasound images (so far I'd declined to look at my scans) and could quite easily see the thickened pleura with whorls of tumour cells literally falling head over heels off into the pleural fluid... Gosh.....A joint decision was taken not to do the pleural biopsy now my lung had expanded, no one wanted fun and games on Friday the 13th!!!

Part 2 – Phone a friend, CT number one and some results, 12 February 2017

Realise that in my last post I referred to my pending CT scan as though it was all arranged. In fact, it wasn't quite as simple as that.

I also realise that I hadn't even told you what all the fuss was about, why I was so worried about the prospect of needing a CT... Well.

In the end, a GP called me back and told me about my chest Xray. She read out the report verbatim. I remember hearing the words 'Moderate pleural effusion, loss of lung volume, pleural thickening, fluid in the horizontal fissure, differential diagnosis: infection or malignancy'. Basically, fluid on the lung, with thickening of the membrane around the lung, likely to be due to infection or cancer.

Could it be TB? I was certainly at risk. I had worked on the Infectious Diseases ward at St James Hospital and knew I had virtually no immunity to TB when last checked. But, I knew that I had no other symptoms of TB.... No fevers or night sweats.... DARN!!!! Now I knew there was a problem, I also knew that it had been going on for a long time, so whatever it turned out to be, was unlikely to be a straightforward infection. I recalled having some right sided chest pain which resolved spontaneously: my GP confirmed this was as long ago as November 2015. Oh dear. I had put this down to commuting with my bike and having pulled a muscle. I was a 'fit' 41y old at the time, why would it have been anything but????!!!!

My mind went into overdrive. I had left work at Mortimer Market Centre as a doctor, and I arrived home dancing the tightrope between doctor and patient. I needed to know what was going on. At this point I hadn't yet been given a date for CT scan.

I had been listed for the Respiratory MDT meeting happening the following week, so this meant that I would definitely get my CT scan before then. I told him I was terrified and would really value seeing him in clinic as a familiar face (I know, probably stepping over the line a little – sorry). He handled me (and my anxiety) very well and suggested that perhaps he wasn't the best person to see me, but one of his colleagues Dr Matt Callister or Dr Kirsty Rodger would be. I didn't know them, or their role, as it had been over 10 years since I had worked in the department. I persuaded myself not to Google them. I was Eternally Grateful for this supportive conversation. Dr John Watson – thank you +++

.....Okay, so I managed to hold off Googling Dr Callister and Rodger for a whole 24 hours. And when I did, it turns out that their specialist interests were lung cancer. Hmmm.

So, the CT happened at Leeds General Infirmary. All quite impressive. Not a huge waiting time. Lots of checking and cross checking of identification and medical history. Didn't have to wear a gown (yay!). CT contrast makes you feel flushed, heart racing, a bit like taking poppers, I would imagine. It also makes you feel as though you are going to wet yourself – who knew?! I felt that I really should have known this having ordered 100's of CT scans, but I didn't. It made me think that perhaps medical/nursing students should actually experience the process of having certain tests, to enable them to be able to explain things to patients more effectively.

The next morning I took the kids to school as usual, arrived home and sat down on the sofa. It was 5 minutes past 9. The home phone rang. No one usually rings this phone, and usually, I don't answer it. But, I had a feeling that I should answer this call. And I was right... It was the GP surgery. Could I go down that morning at 11am to see my usual GP? She had asked to see me. Oh. That doesn't sound good. It felt like each step in the process was confirming what I had dreaded as soon as I'd had the original 'call to CT'.

And, of course, I was right. The CT report was pretty horrendous, and I say that as a glass half full person. To me, it was simply confirming what I had expected, and my lovely GP ended up more upset than I was. I took away a copy of the scan report, which I'm glad, as at the time, the extent of disease didn't really hit me.

Findings: There is irregular, circumferential pleural thickening throughout the right hemithorax associated with a moderate pleural effusion. The pleural disease is nodular and highly suggestive of a malignant process. Passive atelectasis is present in the right lung but no primary lesion or endobronchial disease. The left lung and pleural space are clear and there is no calcification on either side.....

Comment: Malignant looking right-sided pleural disease, for which the differential lies between primary mesothelioma (which seems unlikely in a patient of this age), and metastatic disease.

NB Whenever I have seen the comment 'seems unlikely in this patient because..' written in a radiology report, then that differential turns out to be the correct diagnosis....

I walked up the hill from the GP surgery, with my other half Martin, to Stories cafe in Oakwood <http://www.storiescafe.co.uk> – worth a visit if you live in and around Leeds! Makes me think I could be in beloved East London. And yes, I could still walk and cycle uphill!!! Unusually for me I chose to sit facing away from all the other cafe goers. We sat, and shed some tears, trying to take in the enormity of the result I had just been given. How do you begin to come to terms with a tumour that is circumferential throughout your hemithorax?

Part 1 – the beginning, 5 February 2017

I took the above ‘selfie’ on New Years Day 2017, full of good vibes from the previous evenings celebrations, and hope for the year ahead. I had no idea that within a few days, my life, and that of my precious family, would have taken a bit of a battering, to say the least!

I'd had a bit of a cough, for a few weeks... Well, probably a bit longer than the two months I eventually admitted to my GP. But, I'd put it to the back of my mind and rationalised it, a dry annoying cough, it would go eventually, surely?? Asthma, could I have asthma? Not been wheezy, so unlikely... Maybe it's pertussis, that hangs around for a while... The '100 day cough'... I had far too many other interesting things on, to PrEP Up My Life, than worrying about a cough.

But it didn't go, and I did start to worry. So, the week between Christmas and New Year I finally saw my GP. 'Hmmm, you have slightly reduced air entry at your right base, I'm sure it's nothing to worry about. We need to do a routine Xray anyway'.

So I made my *first* trip to the radiology department in the Bexley Wing. 'Your XRay's not requested on the system' 'Nothing's ever straightforward when it's you doctors' says the receptionist. Great. How did she even know I was a doctor?? 'It's okay – I'll just wait.' And I sat there crocheting a toy monster called 'Bleep' for my 6 year old, trying not to panic. (For any other crochet fans out there see <https://www.edwardscrochet.com/PD.aspx?product=books/-> Edwards_Imaginarium_by_Kerry_Lord)

The Xray happened, after a short wait in a hospital gown tied up so tightly as to not show any naked flesh (aka vulnerability) to the other people (men) waiting (fully clothed), that I almost strangled myself. My panic reached exorbitant levels when the radiographer asked for a lateral film, despite protestations from the technician that it hadn't been requested. She also asked me to see my GP within 48 hours with a deadpan look on her face. 'Oh! But

call first to make sure that they have the result'. Double great. Didn't need my years of work in sexual health, tuned in to the minutiae of body language, to work out that something pretty serious was afoot.

I went back to work after the New Year, and called my GP each day – no result. Then on Thursday 5th January 2017, I got a call. 'Hi love, just the receptionist at your GP surgery. Could you come in this afternoon for your bloods before your CT scan??' And for the second time in a week, time stopped, and my mortality flashed before me. All I could think was 'My kids. My beautiful, beautiful children...'

There was no way I could continue with my clinic and I went in search of trusted colleagues and friends, thankfully in abundance at the lovely Mortimer Market Centre. My clinic was covered (you know who you are – thank you), I was given a time to cry, incredible support from a number of people, and a cup of tea (you all know who you are – thank you), cancelled my clinics for the next week, cycled to Kings Cross and got my planned train back home to Leeds. (For those not aware, I commuted every week from Leeds to London to work taking my bike on the train).

Still completely stunned, I had 'my bloods' done the next morning and had a call later that day to go in for a CT scan on the 10th Jan.

[#notdoingthingsbyhalf – My Mesothelioma Journey](#)

5 Feb 2017

I decided on the blog title after my mum reflected, 'Well, ever since you were a baby, you never did anything by half', and I guess she is right. Sadly, it looks like having cancer is similar... I'm not doing it by half!! Mesothelioma is a challenging cancer to say the least and this will be my story.

Kieran Sweeney YouTube broadcast

<https://www.youtube.com/watch?v=---uMNY55nw4>

I wrote an article in the BMJ in September of 2009. And I'd written the article in February, or March of that year and revised it because it was a bitter, ranting article at the beginning because I was so upset about what had happened. But I wanted to distil some key messages from the piece. So, yes having decided that I would send it to the BMJ, and I knew the BMJ would take it. I'd been in touch with them and said I wanted to do this. And they had seen a draft of it and said they would definitely take it. So, I knew it was going in. And then I got Jocelyn Cornwell, who heads a study in compassion, effectively, at the point of care through the Kings Fund to write the commentary on it, alongside my oncologist, which is how these articles are structured. There was no question of making a complaint. I mean transaction there was dealt with brilliantly by my local hospital. There was no hesitation about that. It was just the debacle about the conse...the subsequent unfolding of the story, of the narrative of my diagnosis that was deeply disagreeable.

The diagnosis was established very quickly after I'd had an x-ray, which had shown pleural effusion of my right lung. I'd had some symptoms; a cough, which I thought was a viral infection, for about eight weeks. But because it persisted, I asked my GP for an x-ray. At that point, he set up very quickly an appointment with a respiratory physician who in turn set up an appointment with a cardio-thoracic surgeon for a biopsy. And really, the whole procedure from being referred to having the biopsy, took place over about a week. And I think, actually, operationally couldn't have happened any more quickly.

So, technically things went very swiftly and very positively. But it was after I'd had the biopsy, which was again...the anaesthetist was round and asking me was I okay, and the third surgeon came round and asked me was I okay after the biopsy. But what was interesting was; they all looked very, very despondent about their findings. Their findings were on a video assisted thoracoscopy. So, everyone could see my chest, which looked terrible, looking at the reports. And increasingly I became aware of their despondency. So, I got more frightened, really, as that period went on. And I remember the SHO coming into the room; he'd been an under-graduate student with me for a year or two; I knew him very well. I could tell that he was very, very upset and wanted to talk to me about it. But I think he felt that he didn't have the authority to do that.

I left hospital the next day still without any clear understanding of what was happening to me. And came home to the kitchen in my house, where I opened the discharge summary, because I have access to my own records, obviously. And the discharge summary included the phrase likely malignant mesothelioma; patient aware of diagnosis. So, that's how I learned that I had mesothelioma. Reading it at the kitchen table. I think it's important to say at this stage that although that wasn't the right way to learn about it, I think everyone was trying to do the right thing. And the first I learned directly that I might have mesothelioma was from the specialist cancer nurse who came in to show my wife how to drain the pleural catheter, which was in my right chest. And he, again, acting very conscientiously said to me and my wife; if I wanted any information about mesothelioma, he had lots of it available.

But there was a point where everyone in the team, including my wife, knew I had mesothelioma and I didn't. And that can't be right. I think there may have been something in the fact that, being a doctor and being roughly the same age as these guys; I'm in my late fifties. Most of the consultants were in their late fifties, or fifties. You know? And our kids would be the same age. I...this is completely curtains this diagnosis. So, you could see them thinking, god this guy's out [text unclear]. And they just weren't...they weren't brave enough. They weren't brave enough to say, this is really bad news for you. Maybe they hid behind the science of their biopsy and pathology to avoid confronting the metaphysics of my predicament. I am a man devoid of hope and I just sense that they hesitated at that point and my own view is...sounds quite hard...is that I just don't think it's good enough.

Medicine is not a...solely a technical activity and pursuit. Medicine is about understanding and being with people at the edge of the human predicament. Caring for somebody as a transactional activity, where they do things to me. Everything I've had done to me in the...our local hospital, has been excellent. There hasn't been a single mistake, I'm seen on time for things. Transactionally, I think the place is outstanding. It's the relational care where I've thought...I've felt that the experience has been less than satisfactory. And it's been a mixture of some really shockingly bad interactions and some shockingly good interactions; some surprisingly good interactions. But again, I want to stress that when people...when I perceive people to be interacting poorly with me, I still...and I mean this, I still think they are trying to do their best. I still think they're...they think that they're...they don't think that they're actually upsetting me, in a particular way. But they are. And my insight into the experience is, that it doesn't take much to change from upsetting, or insensitive communication to communication that puts someone much more at their ease.

I think that there are a number of, sort of, interactive, bear traps, one can fall into. And one of the problems is actually quite a sophisticated problem, which is that the healthcare professional does their job and for many people this job is pretty mundane; they're doing the same kind of thing to the same kind of people pretty well every day. So, for them that activity becomes completely routine and, on some days, rather dull.

For the individual, it's anything but that. It's anything but that. Every individual that comes through a hospital is apprehensive. It's a strange place, you lie in a strange bed that's very firm, you have strange sheets, you have odd tea in a plastic cup. The whole thing is vibrantly different.

But one of the examples, that particularly seemed to upset me and I'm not sure if this is just me being oversensitive; it's people saying, do this, for me, put your hands behind your back, for me, turn your arm out, for me, hop up on the bed, for me, just tell me your date of birth, for me. And I'm...I've mulled over whether this is just me being grumpy, which is possible, or whether there's something more important. And I would defend myself by saying, I think it is important. Because I think there's something about a locus of control. If somebody says to you, do this for me, they are retaining control over that transaction. And I think that's a class example of being cared for; being transactionally involved and not being cared about. Where they don't know really who I am. They don't really care who I am. I think people...I think individual healthcare professionals inadvertently heap small humiliations repeatedly on patients and they do it inadvertently. I stress...and I mention that it's inadvertently. An example that got me early on in my days of having CAT scans was, that I was told to undress...instructed to undress.

The phrase they used was, we need to get you to get your clothes off, down to your pants. And you're wearing pants, and socks, and shoes. That's a cool sartorial combination, which I have to say I don't indulge in very frequently in myself, except when I'm having CAT scans. So, you're with pants, and socks, and shoes and this gown that you hope is fastened at the back and not exposing your bum to the radiology world. But I'm sitting there with a plastic... green plastic bag, holding my clothes, hoping the back of my gown was closed, when a senior radiographer walked briskly into the patients' area and said, Kieran Sweeney, follow I. And like a sheep dog, I just got up and followed this guy. But I didn't know what was going to happen next. But...you know? But this crass attempt at humour, follow I, just humiliated me. I felt just utterly degraded. I felt seriously upset by it. That he should so trivialise what was for me a shocking passage into my healthcare problem; I'm so angry about that. Now, I think, he was doing it inadvertently...I think he was trying to be...I don't know what he was trying to be; witty or funny or something. But you just can't do that. You've got to be awful careful about doing that, really.

Rediscovering the humanity in a patient, I think is a lovely phrase. And I can...and I think it's an infinitely rewarding pursuit for healthcare professionals, to pursue, to take an interest in. That's really why I came into medicine. It was to be with people at the edge of the human predicament but to understand them when they were there. And to some extent to let them understand me, being with them, at that point; at the edge of the human predicament. Now, let's not beat about the bush here, that's what doctors do. You know? That's our job. And it's a hard old job. And it does require technical competence but well beyond that, the competence of the serious individual. I mean, society needs to understand that only serious people can be healthcare professionals. Because it's a deadly serious job, really. And inside that job, if you are able to identify the humanity of the patients, as well as provide them with technical competence; it's such a win-win situation. It's so rewarding for the patient, to be treated sensitively and technically competently. And for the healthcare professional to feel that they've touched that patient in a way that has technically helped them but also regarded them and understood them as an individual.

Appendix 4

FOI email response

From: **FOI** <FOI@resolution.nhs.uk>
Date: Mon, Oct 7, 2019 at 2:45 PM
Subject: Injury coding FOI_3992
To: Peter A <peterallmark@gmail.com>

Dear Peter Allmark,

I have checked with our claims team and they have confirmed me that the coding string relates solely to mesothelioma. It will not pick up other lung disease injuries.

With regard to the gender breakdown please see tables 6 and 7 in the attached.

We are unable to provide a breakdown by occupation/employee type as this is not recorded separately. We would need to manually review each claim file to extract this information. At a conservative 5 minutes to review each successful claim it would take approx. 46 hours to extract the occupation data.

Therefore, we estimate that the cost of complying with the request in its entirety would exceed the 'appropriate limit'. Section 12(1) of the Freedom of Information Act is a provision which allows a public authority to refuse to comply with a request for information where the cost of compliance is estimated to exceed a set limit (known as the 'appropriate limit'). The 'appropriate limit' for NHS Resolution is £450. This equates to 18 hours of work at the rate of £25 per hour set out in the 'Fees Regulations'.

Appendix 5

Full FOI response



Resolution

2nd Floor
151 Buckingham Palace Road
London
SW1W 9SZ
Telephone: 020 7811 2700

October 2019
FOI_3992

The following information was requested on 3 September 2019:

Information Request: I am a researcher undertaking a project for the charity, Mesothelioma UK. I would like to know about civil law cases of negligence that have been taken against the NHS with regard to current or former NHS employees who have developed mesothelioma and have sued because they believe it to be due to asbestos exposure at work. I would be interested to know cases in the last fifteen years (or less if information is available but not for that period).

Any information would be helpful but, if possible, I'd like to know, for each year: i) Number of cases received; ii) Number of cases settled in favour of the employee, number of cases with out-of-court settlement and number of cases settled in favour of the NHS.

I would also like to know (again, if information is available): iv) employee type; v) employee gender.

Our Response

Please find attached the information we are able to provide. By way of advice and assistance and further to our obligations under s. 16 FOIA, NHS Resolution manages a number of risk- pooling schemes (similar to insurance) for the NHS, one of which is the Liability to Third Parties Scheme (LTPS). This covers both employers' liability (i.e. in relation to duties of care owed to employees) and public liability (i.e. in relation to duties of care owed other patients, visitors and other members of the public). You can find out more about the LTPS scheme here: <https://resolution.nhs.uk/services/claims-management/non-clinical-claims/risk-pooling-schemes-for-trusts/liabilities-to-third-parties-scheme/> . The attached data is drawn from data from that scheme.

Please see the following link for how data is recorded in the Claims database: Glossary

We have suppressed (using a #) low figures and are unable to provide a breakdown by iv) employee type; v) employee gender as we believe that disclosure of information with this level of granularity is exempt under Section 40(2) by virtue of section 40(3)(a)(i) of the Act, where disclosure to a member of the public would contravene one or more of the data protection principles. The data protection principles are set out in Article 5 of the General Data Protection Regulation.

In some instances the low numbers of claims (fewer than 5) in each injury or cause category, the likelihood exists that individuals who are the subject of this information may be identified either from this information alone, or in combination with other available information. In addition to this, as this information is considered to be sensitive personal data (the data subjects' medical condition);

NHS Resolution believes it has a greater responsibility to protect those individuals identities', as disclosure could potentially cause damage and/or distress to those involved.

This concludes our response to your request.

If you are not satisfied with the service that you have received in response to your information request, it is open to you to make a complaint and request a formal review of our decisions. If you choose to do this, you should write to Tinku Mitra, Head of Corporate and Information Governance for NHS Resolution, within 28 days of your receipt of this reply. Reviews of decisions made in relation to information requests are carried out by a person who was not involved in the original decision-making about the request.

If you are not content with the outcome of your complaint, you may apply directly to the Information Commissioner for a review of the decision. Generally, the Information Commissioner will not make a decision unless you have exhausted the local complaints procedure. The address of the Information Commissioner's Office is: Wycliffe House Water Lane Wilmslow Cheshire SK9 5AF

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Freedom of Information Request# 3992 Data correct as at: 2019-08-31

NB: Number of claims fewer than five (and any associated values, within the same row) are masked with a '#' (in accordance with Data Protection guidelines). Accordingly, some total values may also be approximated to prevent masked values to be deduced through reverse calculation.

Table 1: Number of Claims received between financial years 2004/05 to 2018/19 injury coding: Injuries to Internal Organs\Lung Disease\Mesothelioma

Table 2: Number of claims with a damages payment - resolved in favour of employee between financial years 2004/05 to 2018/19 injury coding: Injuries to Internal Organs\Lung Disease\Mesothelioma

Table 3: Number of claims without a damages payment - resolved in favour of NHS between financial years 2004/05 to 2018/19 injury coding: Injuries to Internal Organs\Lung Disease\Mesothelioma

Table 4: Number of claims resolved at trial (having gone through the status 'Damages Approved/Set By Court') between financial years 2004/05 to 2018/19 injury coding: Injuries to Internal Organs\Lung Disease\Mesothelioma

Table 5: Number of claims resolved out of court (not having gone through the status 'Damages Approved/Set By Court') between financial years 2004/05 to 2018/19 injury coding: Injuries to Internal Organs\Lung Disease\Mesothelioma

Table 6: Number of Claims received by Gender between financial years 2004/05 to 2018/19 injury coding: Injuries to Internal Organs\Lung Disease\Mesothelioma

Table 7: Number of claims with a damages payment - resolved in favour of employee by Gender between financial years 2004/05 to 2018/19 injury coding: Injuries to Internal Organs\Lung Disease\Mesothelioma

Freedom of Information Request# 3992 Data
correct as at: 2019-08-31

**Table 1: Number of Claims received between
financial years 2004/05 to 2018/19 injury
coding: Injuries to Internal Organs\Lung
Disease\Mesothelioma**

Notifications Y
Clinical_NonClinical Non Clinical
ScheduleName Empl Liab

Notification Year	No. of Claims
2004/05	38
2005/06	27
2006/07	29
2007/08	28
2008/09	47
2009/10	59
2010/11	63
2011/12	72
2012/13	80
2013/14	176
2014/15	119
2015/16	114
2016/17	109
2017/18	120
2018/19	148
Grand Total	1,229

Freedom of Information Request# 3992 Data
correct as at: 2019-08-31

**Table 2: Number of claims with a damages
payment - resolved in favour of employee
between financial years 2004/05 to 2018/19
injury coding: Injuries to Internal Organs\Lung
Disease\Mesothelioma**

Notifications
Clinical_NonClinical
ScheduleName

Y
Non Clinical
Empl Liab

Year of Closure (Settlement Year for PPOs)	No. of Claims	Damages Paid	Defence Costs Paid	Claimant Costs Paid	Total Paid
2004/05	15	60,348	13,872	81,641	155,860
2005/06	15	107,770	33,498	117,573	258,841
2006/07	12	161,225	36,669	162,028	359,923
2007/08	22	896,688	117,559	324,504	1,338,751
2008/09	25	311,946	100,090	397,455	809,491
2009/10	9	41,855	21,891	95,725	159,471
2010/11	24	174,862	48,969	242,336	466,167
2011/12	44	1,001,944	123,098	558,607	1,683,649
2012/13	43	1,792,738	156,036	584,180	2,532,955
2013/14	53	724,493	145,880	676,579	1,546,952
2014/15	66	2,876,357	278,494	1,484,270	4,639,121
2015/16	61	4,656,372	387,871	1,915,098	6,959,341
2016/17	67	2,688,737	346,158	1,199,072	4,239,751
2017/18	38	1,103,831	179,837	611,242	1,897,660
2018/19	59	2,966,325	438,331	1,491,981	4,896,637
Grand Total	553	19,565,492	2,428,253	9,942,291	31,944,570

Freedom of Information Request# 3992 Data
correct as at: 2019-08-31

Table 3: Number of claims without a damages payment - resolved in favour of NHS between financial years 2004/05 to 2018/19 injury coding: Injuries to Internal Organs\Lung Disease\Mesothelioma

Closed_Settled
Clinical_NonClinical
Claim_Outcome_FOI
Schedule Name

Y
Non Clinical
NIL Damages
Empl Liab

Year of Closure (Settlement Year for PPOs)	No. of Claims	Damages Paid	Defence Costs Paid	Claimant Costs Paid	Total Paid
2004/05	16	0	4,407	320	4,726
2005/06	14	0	8,811	0	8,811
2006/07	22	0	9,338	1,163	10,501
2007/08	25	0	19,740	38,374	20,712
2008/09	16	0	26,458	2,232	28,690
2009/10	20	0	15,669	1,980	17,649
2010/11	13	0	2,426	108	2,534
2011/12	20	0	2,888	1,025	3,913
2012/13	24	0	5,813	460	6,273
2013/14	38	0	18,801	85,575	104,376
2014/15	70	0	70,732	117,030	187,762
2015/16	48	0	44,380	6,103	50,483
2016/17	70	0	159,705	6,310	166,015
2017/18	42	0	77,363	622	77,985
2018/19	69	0	127,678	2,970	130,648
Grand Total	507	0	594,208	264,272	821,078

Freedom of Information Request# 3992 Data
correct as at: 2019-08-31

**Table 4: Number of claims resolved at trial
(having gone through the status 'Damages
Approved/Set By Court') between financial
years 2004/05 to 2018/19 injury coding:
Injuries to Internal Organs\Lung Disease\
Mesothelioma**

Closed_Settled	Y
Clinical_NonClinical	Non Clinical
Claim_Outcome_FOI	Damages Paid
Trial_Outcome	(Multiple Items)
ScheduleName	Empl Liab

Year of Closure (Settlement Year for PPOs)	No. of Claims	Damages Paid	Defence Costs Paid	Claimant Costs Paid	Total Paid
2013/14	#	#	#	#	#
2015/16	#	#	#	#	#
Grand Total	#	#	#	#	#

Freedom of Information Request# 3992 Data
correct as at: 2019-08-31

**Table 5: Number of claims resolved out of court
(not having gone through the status 'Damages
Approved/Set By Court') between financial
years 2004/05 to 2018/19 injury coding:
Injuries to Internal Organs\Lung Disease\
Mesothelioma**

Closed_Settled
Clinical_NonClinical
Claim_Outcome_FOI
Trial_Outcome
ScheduleName

Y
Non Clinical
Damages Paid
(Multiple items)
Empl Liab

Year of Closure (Settlement Year for PPOs)	No. of Claims	Damages Paid	Defence Costs Paid	Claimant Costs Paid	Total Paid
2004/05	15	60,348	13,872	81,641	155,860
2005/06	15	107,770	33,498	117,573	258,841
2006/07	12	161,225	36,669	162,028	359,923
2007/08	22	896,688	117,559	324,504	1,338,751
2008/09	25	311,946	100,090	397,455	809,491
2009/10	9	41,855	21,891	95,725	159,471
2010/11	24	174,862	48,969	242,336	466,167
2011/12	44	1,001,944	123,098	558,607	1,683,649
2012/13	43	1,792,738	156,036	584,180	2,532,955
2013/14	51	694,995	101,978	606,429	1,403,401
2014/15	66	2,876,357	278,494	1,484,270	4,639,121
2015/16	60	4,051,218	322,738	1,465,098	5,839,054
2016/17	67	2,688,737	346,158	1,199,072	4,239,751
2017/18	38	1,103,831	179,837	611,242	1,897,660
2018/19	59	2,966,325	438,331	1,491,981	4,896,637
Grand Total	550	18,930,839	2,319,218	9,422,141	30,680,732

**Freedom of Information Request# 3992 Data
correct as at: 2019-08-31**

**Table 6: Number of Claims received by Gender
between financial years 2004/05 to 2018/19
injury coding: Injuries to Internal Organs\Lung
Disease\Mesothelioma**

Notifications	Y
Clinical_NonClinical	Non Clinical
ScheduleName	Empl Liab

Notification Year	No. of Claims
Female	644
Male	585
Grand Total	1,229

Freedom of Information Request# 3992 Data
correct as at: 2019-08-31

**Table 5: Number of claims resolved out of court
(not having gone through the status 'Damages
Approved/Set By Court') between financial
years 2004/05 to 2018/19 injury coding:
Injuries to Internal Organs\Lung Disease\
Mesothelioma**

Closed_Settled
Clinical_NonClinical
Claim_Outcome_FOI
ScheduleName

Y
Non Clinical
Damages Paid
Empl Liab

Year of Closure (Settlement Year for PPOs)	No. of Claims	Damages Paid	Defence Costs Paid	Claimant Costs Paid	Total Paid
Female	281	8,483,868	1,141,663	5,112,700	14,746,765
Male	272	11,081,624	1,286,590	4,829,591	17,197,805
Grand Total	553	19,565,492	2,428,253	9,942,291	31,944,570



MESOTHELIOMA UK

Mesothelioma Charitable Incorporated Organisation

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Registered Charity Number 1177039