

## **Written evidence from Professor Angela Tod on behalf of the Mesothelioma UK Research Centre Sheffield (MURC)**

We thank the Work and Pensions Committee for inviting evidence as part of the inquiry into how the Health & Safety Executive manages the continued presence of asbestos in buildings.

The MURC was established in July 2020 to conduct research into the experience of mesothelioma from the perspective of those with a diagnosis and their families. Mesothelioma is a terminal diagnosis with no curative treatment. The main cause of mesothelioma is exposure to asbestos. Exposure often takes place many years before diagnosis, creating challenges in terms of determining where exposure took place.

Our research mainly involves capturing experience through individual or group interviews, or survey methods. A full overview of our research can be found on our website <https://www.sheffield.ac.uk/murc>. In this document we draw in the main on evidence from three studies

1. The Mesothelioma Asbestos Guidance Study (MAGS) – exploring the experience of people working in healthcare who develop mesothelioma ( <https://www.mesothelioma.uk.com/report-published-on-military-experiences-of-asbestos-related-cancer/> )
2. The Gendered Experience of Mesothelioma (GEMS)
3. The Military Experience of mesothelioma Study (MiMES)

We would like to submit evidence in relation to the following questions:

- What are the current risks posed by asbestos in the workplace? Which groups of workers are most at risk?
- Does HSE keep adequate records of asbestos in public buildings?

### ***What are the current risks posed by asbestos in the workplace? Which groups of workers are most at risk?***

From the accounts of our research participants, it is clear that there are a wide range of workplaces that can lead to asbestos exposure. Following the paper by Rake et al (2009) focus has been on occupations where people are put at high risk of exposure, such as construction trades, and dockworkers. However, in our studies participants had a more diverse occupational history. This, and other findings, indicate that people working in occupations other than those traditionally seen as high risk can also lead to asbestos exposure. A key issue here is that asbestos related diseases (ARD) such as mesothelioma can occur with a small amount of asbestos exposure. Therefore, working in buildings with asbestos in situ can also create a risk of ARD such as mesothelioma. Examples of evidence from our studies are as follows:

## MAGS

This study explored the experience of healthcare workers with mesothelioma due to exposure in their work. Part of the study involved analysis of data from a Freedom of Information (FOI) request to NHS Resolutions asking for information on *'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'*

This analysis indicated the following

- Between 2002-15, the ONS/HSE recorded/Reported 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.
- Another reason for suspecting this is an underestimate is that 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.
- People who work in healthcare may not have this occupation declared and thus be picked up in ONS/HSE data. For example, a nurse who leaves to take up another career or role e.g. lecturer or a worker who works in a healthcare environment but where the occupation is recorded but not the workplace e.g. cleaner, laundry worker
- We do not know the breakdown by occupation as this was not provided by NHS Resolution on the basis of cost. It would be helpful to know whether professional or ancillary staff are more likely to make a legal claim.

The study also involved individual interviews with healthcare workers with mesothelioma or family members. Analysis of the interview data indicated the following:

- There was a lack of awareness amongst participants about the risk of asbestos exposure in healthcare environments.
- Participants expressed disappointment, highly specific to NHS staff, 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 participant 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.

## **MIMES**

This study explored the experiences of UK military veterans with mesothelioma following asbestos exposure during their military service. This study involved analysis of national datasets and interviews with UK military veterans with mesothelioma and their family members. The findings indicate the following:

- The national datasets indicated that the occupation of the veterans with mesothelioma was not just in high-risk jobs e.g. electrician, engineer and seaman. Cases were also recorded of people with mesothelioma exposed to lower levels of asbestos e.g. due to workplace, living or training environments.
- There were a range of situations in which the interview participants had been exposed to asbestos. In many cases veterans had not been aware of the dangers of asbestos until many years after the exposure had occurred. Ongoing exposure to asbestos was also highlighted as a concern discussed.
- Many had been unaware of the dangers of asbestos at the time they were exposed.
- Their exposure reflected the varied nature of military work and life. Living accommodation, combat experiences and extensive travel were identified as potential sources of exposure to asbestos.

- **Living Accommodation**

Some of the examples of asbestos exposure provided by the participants include Nissen huts, living on board ships and living in old factories. Some participants mentioned accommodation during training. This indicates that domestic exposure for military veterans is distinct from domestic exposure for civilians. For those in military service, the employer (MOD) would often have been the provider of the accommodation and therefore responsible for providing a safe living environment as well as a safe working environment.

- **Combat**

Participants also described examples where combat may have exposed them to asbestos, for example "searching bombed out" buildings, bomb blasts and searching for ammunition in old buildings/factories. Some

participants discussed actually working in buildings that had been bombed. This is a type of exposure which would not usually need to be considered when conducting a civilian occupational history. This illustrates how having an Armed Forces background may create specific challenges when undertaking an occupational asbestos exposure history.

- Extensive travel

Most of the veterans had experienced extensive travel during their service, both nationally and internationally. This meant, pinpointing the exact location of exposure was not always possible

- Some veterans and family members described how exposure to asbestos had been ongoing over years, despite evidence of the harm that it can cause. Concerns were expressed about Crown properties, which still contain asbestos, falling into disrepair.

*'I could take you to probably thousands of crown estates properties from airfields to ships, from ships to army training centres, from army training centres to aircraft, stately homes, public buildings, even to the Palace of Westminster itself, which has an acute problem of asbestos.'*

## GEMS

This study explored the gendered experience of mesothelioma. This study indicated that:

- High risk occupations for men differed from high-risk occupations for women
- Women of all ages and younger men lacked awareness of the dangers of asbestos exposure.
- From the analysis of data from an Asbestos Support Group and the interview transcripts, there is an indication that the list of occupations where women were exposed to asbestos differed from that of men. Men were most frequently exposed in construction-related occupations due to direct handling of asbestos.
- The findings show that, for women, exposure at work was most frequently linked to the working environment rather than the direct handling of asbestos and the most frequent occupation was that of administration e.g. office work.
- The interview data also noted these differences in occupational exposure to asbestos. Four of the women interviewed were secretaries and others worked in administrative roles.
- For other women interviewed, para-occupational exposure was commonly considered the most likely source of asbestos exposure. However, some women who initially thought that para-occupational exposure was their only source of exposure later found that they may have been exposed through their own work.
- *'I was a setter's mate. [...] there was asbestos all around the burners. But I didn't know all that, I'd gone into all that myself and realised that's where the asbestos was. I've only just really been looking at it. So, I didn't know really until about two years ago that there had been a case that won. So,*

*there was a case. I only found out through another support group that said to me 'oh yeah, we've had a case.'*

- Unlike Rake et al (2009), GEMS did not find that the occupational risk in women was concentrated in industrial settings, since many women in the GEMS had occupation types based in environments such as office blocks, schools and hospitals (Senek et al 2020).
- GEMS suggests that long-term, low-level exposure to asbestos could be causing an increase in the prevalence of mesothelioma among people working in low-risk occupations, who tend to be women. A high proportion of mesothelioma cases among people employed in low-risk occupations would suggest that long-term, low-level exposure is a concern. Further research in this area is required. (Senek et al 2020).
- The emphasis on the risk of asbestos exposure in high-risk occupational branches such as the construction industry may have obscured the risk associated with long-term, low-level exposure resulting from working in ageing buildings potentially contaminated with asbestos. (Senek et al (2020).

Selected relevant publications are listed below.

Allmark A, Tod A, Darlison L (2020) Mesothelioma: are nurses being put at risk in the workplace? *Nursing Standard* 35(12):14-16 <https://rcni.com/nursing-standard/features/mesothelioma-are-nurses-being-put-risk-workplace-168506>

Ejegi-Memeh S, Robertson S, Taylor B, Tod A. Gender and the experiences of living with mesothelioma: A thematic analysis. *European Journal of Oncology Nursing*. Vol 52, June 2021. <https://doi.org/10.1016/j.ejon.2021.101966>

Ejegi-Memeh S, Darlison L, Moylan A, Tod A, Sherborne V, Warnock C, Taylor B. Living with mesothelioma: A qualitative study of the experiences of male military veterans in the UK. *European Journal of Oncology Nursing*. Volume 50, February 2021 <https://doi.org/10.1016/j.ejon.2020.101889>

Rake et al (2009) Occupational, domestic and environmental mesothelioma risks in the British population: a case-control study *Br. J. Canc.*, 100 (2009), pp. 1175-1183, [10.1038/sj.bjc.6604879](https://doi.org/10.1038/sj.bjc.6604879)

Senek M, Robertson S, Tod A et al. Mesothelioma: exploring gender differences in time to diagnosis, seeking legal advice and occupational risk. *Cancer Nursing Practice*. 2020 [doi: 10.7748/cnp.2020.e1745](https://doi.org/10.7748/cnp.2020.e1745)

Sherborne, V, Seymour, J, Taylor, B, Tod, A. What are the psychological effects of mesothelioma on patients and their carers? A scoping review. *Psycho-Oncology*. 2020; 29: 1464– 1473. <https://doi.org/10.1002/pon.5454>  
2019

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