

Written evidence submitted by Mesothelioma UK Research Centre – Sheffield

Experiences of female Armed Forces veterans who died from mesothelioma

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Introduction

In July 2020 the Mesothelioma UK Research Centre was established at The University of Sheffield, funded by the charity Mesothelioma UK. The Research Centre is based in the Division of Nursing and Midwifery at the Health Sciences School.

The aim of the Mesothelioma UK Research Centre – Sheffield is to conduct a portfolio of robust and rigorous research with a reputation for excellence. The goal is for the research to benefit the care of people diagnosed with mesothelioma and their families. The Research Centre is funded by Mesothelioma UK, a charity and national specialist resource centre, specifically for the asbestos-related cancer, mesothelioma. Mesothelioma UK are dedicated to providing specialist mesothelioma information, support and education, and to improving care and treatment for all UK mesothelioma patients and their carers.

The Research Centre has recently conducted a mixed methods study exploring the UK veteran experience of living with mesothelioma (MiMES). This was funded as part of Mesothelioma UK's 'Supporting Our Armed Forces' initiative (SOAF), and included funding for a PhD student, Virginia Sherborne. In October 2020 Virginia completed a secondary data analysis of transcripts from MiMES interviews with veteran mesothelioma patients and/or their informal carers. She then began conducting interviews with carers of British veterans with mesothelioma, focussing on the psychological impact of the disease. Two examples of female veterans' experiences stood out from the interview data as relevant to the Select Committee's remit, in particular its interest in whether the needs of female veterans are currently met by the available services. These examples are presented below, in anonymised form. Both interviews were carried out with the carer after the veteran had died.

Janet's story

Janet served in the RAF, and later worked as a contractor for the MOD until her retirement. She died from malignant pleural mesothelioma in her 60s. Her Armed Forces service was the most probable source of her exposure to asbestos. When Janet collapsed with symptoms of mesothelioma, she was wrongly diagnosed with and treated for chronic obstructive pulmonary disease (COPD). Her condition deteriorated and she was diagnosed with mesothelioma only three months before her death. She received compensation from the MOD for her industrial injury.

Janet's husband Malcolm (also a veteran) described the impact of the misdiagnosis:

"I'd lost my wife, she'd survived six months. I was capable of being on my own because I'd been on my own as a result of my job. I'd been on my own many times before, and so had she been on her own, so being on our own didn't cause a problem to either of us. But it was the nature in which Janet had died so

suddenly, with a disease, an industrial disease that only a few months before we didn't know that she had got."

Marie's story

Marie also served in the RAF, and later worked as a contractor for the MOD. She died in her 40s from peritoneal mesothelioma. Marie's illness too was misdiagnosed. This led to her cancer being untreated for a whole year. It had spread widely by the time she was correctly diagnosed. Initially, the investigating consultant told Marie she could not possibly have mesothelioma. Gary explained that she was told, "You're too young, you've not worked in an industrial background, you haven't got it."

Great distress was also caused to Marie and her husband Gary (both veterans) by the fact that the MOD refused to accept her cancer had been caused by asbestos exposure. Officials argued that peritoneal mesothelioma was not caused by asbestos, despite Marie's consultant oncologist writing to confirm that this was the case. Marie had to engage lawyers to sue the MOD to obtain compensation, even though she remembered being exposed during her service years. Gary explained, "We met in basic training in the RAF, we had to scrub the walls, the pipes, everything, the pipes were laden with asbestos, she breathed it in, they killed her, that's it."

Gary also described the impact of Marie's difficulties with the NHS and the MOD:

"So, I had [NHS Trust] had a failing of trying to get my wife proper treatment and the MOD not backing up, and I've just left, really, two years earlier the RAF, after a full career in the RAF and the army, and we've lived our lives travelling around with the MOD and I was like, "What is the, what is the problem?"

Conclusion

The experiences of Marie and Janet illustrate how the needs of female veterans may not be being met by the available services. The delay in getting a correct diagnosis matches the findings of a recent UK research study⁽¹⁾, which looked at gender differences in mesothelioma. Women with pleural mesothelioma are often diagnosed later than men, possibly because healthcare professionals have a greater awareness of mesothelioma risk in traditionally male occupations. For women with peritoneal mesothelioma, other gynaecological diseases are often considered as likely diagnoses first. In their report of the MiMES study⁽²⁾, Ejegi-Memeh et al. showed that the pattern of exposure to asbestos was different for veterans compared to civilians. As well as occupational exposure from working directly with asbestos (e.g. maintenance of Sea King helicopter wiring), military personnel could have indirect exposure. This could arise from living accommodation (e.g. on board ships), combat experiences (such as searching bombed out buildings) and extensive travel. Domestic exposure for military veterans is therefore distinct from domestic exposure for civilians.

To sum up, it is important that services provided both within the MOD and in the civilian health environment are aware that female veterans may have an increased risk of exposure

to asbestos as a result of their military service compared to non-veteran women. This would help suspicions of asbestos-related diseases such as mesothelioma to be raised at an earlier stage, increasing access to effective treatment and improved quality of life. It would also allow female veterans to receive the compensation they deserve in a timely manner.

1. Senek M, Robertson S, Tod A, Squibb M. Mesothelioma: exploring gender differences in time to diagnosis, seeking legal advice and occupational risk [Internet]. [cited 2020 Dec 14]. Available from: <https://journals.rcni.com/cancer-nursing-practice/evidence-and-practice/mesothelioma-exploring-gender-differences-in-time-to-diagnosis-seeking-legal-advice-and-occupational-risk-cnp.2020.e1745/abs>
2. Ejegi-Memeh S, Taylor B, Tod A, Darlison L. Military Experience of Mesothelioma Study (MiMES) - Mesothelioma UK. 2020.

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