

Text of Presentation by Siobhan Brewer

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My name is Siobhan Brewer and I am the daughter of Debbie Brewer, whom many of you will know as a prominent asbestos campaigner here in the UK. I am standing here because my mum, who was meant to be speaking to you today, very sadly succumbed to her illness just a few weeks ago.

Mum was diagnosed with mesothelioma in November 2006, at the age of forty-seven. She was exposed to asbestos on her father's overalls after he came home from his work as a lagger at Devonport Dockyard. She would have been four years old at the time.

I can remember the first meeting with the doctor who was supposed to be my mum's oncologist. We sat in the waiting room in Plymouth's Derriford Hospital and watched as people took a number and waited to be called over the tannoy to their various appointments. We were horrified to see their lives being reduced to the same kind of system you get at a supermarket meat counter. Then we spoke to the doctor, who told her bluntly that most patients diagnosed with mesothelioma die within six to nine months. We both broke down crying and he left very swiftly afterwards, handing us over to the specialist nurse - the only staff member to show us any compassion.

I have always looked back on that day with anger. It was one of the most difficult days of my life, but the system seemed to place no value on us. We felt shuffled in and out quickly with little regard to the devastating news we'd just received.

There were few options open to us for treatment. The oncologist had listed three possible chemotherapy drugs but said that he could not give my mum what he described as the 'best' one, Alimta, because at the time it was not available on the NHS. We were very lucky that my mum's employers provided health insurance, which enabled her to go private and get a second opinion from a much more positive oncologist. He told us that he had seen people with mesothelioma go on for anything from six months to ten years, which gave us a lot more hope.

At the time, it was simple enough to find medical information about mesothelioma, but difficult to find other people with the disease to talk to so we set up a website where my mum shared all of her thoughts, feelings and experiences with mesothelioma. People soon started to email and call and she was always happy to give them some of her time. Even on her worst days, she was a kind and caring woman who couldn't turn away someone in need.

Through the community she'd helped to establish, she found out about lots of different things to try and fight off the cancer, but it continued to grow. The turning point came when she discovered a clinical trial being carried out by Professor Thomas Vogl in Frankfurt. In May 2008, she travelled to Germany with a friend. She came back a different person.

My mum described Professor Vogl's approach as completely different to the other oncologists. While he made it clear that this was not a cure, for the first time someone had said that they would help her. She had six chemoembolization treatments over the course of the year, and her CT scans showed a dramatic 83% reduction of the tumour during this time, whereas in the previous year it had grown. Mum believed this treatment added years to her life, without the harsh side-effects of chemotherapy, and was passionate about sharing it with other cancer patients.

The cancer began to spread to a lymph node in late 2009 and was treated effectively in the UK using radiotherapy. She also had conventional chemotherapy here using Alimta in 2012, which seemed to slow the growth but finally in 2013 she could do no more. Her condition was complicated by a fistula which gave her a lot of problems with chest infections, which in turn were difficult to treat because of allergic reactions to antibiotics. She gradually became weaker and finally passed away on the 9th of June this year.

She was looking forward to coming today, and if she was here I think she would have been pleased to see the government has recognized the plight of mesothelioma patients. But she would be disappointed with the Mesothelioma Bill in its current form, as am I.

First of all, it is disgraceful to only award payments to those diagnosed after the 25th July 2012. There is no moral or ethical reason why this should be the case. To deny compensation to some while others receive is as unfair as the illness itself.

Secondly, my mum would have been appalled at the idea of awarding people just 70% of the average claim amount if their employer or insurer cannot be found.

While £87,000 is not an insignificant figure, it offers little recompense to people who have worked hard all of their lives, contributing to the UK economy and suffering wrongly for doing so. Mesothelioma patients don't have many options available on the NHS. If, like my mum, they find something that helps them outside the UK then that money is eaten up very quickly by the costs of travel and accommodation as well as the treatment itself. I cannot divulge the exact figure we received as compensation from the MOD but I can tell you it was more than £87,000 and we still had to raise funds ourselves for mum's final treatment.

We were given more than the figure that has been proposed and still, we struggle. At present, I do not even know if I will be able to keep our modest family home as I have no job, a direct result of having to care for my mum full-time during her illness – saving the government more money. My mum had to choose whether to spend her payout on treatment to extend her life, or to provide a secure financial future for her children and she chose life. I defy anyone here to say that they would not have done the same.

People diagnosed with mesothelioma and their families find themselves helpless in the face of a terrible illness through no fault of their own. I believe no moral government should deny full justice to those who have already already been denied their full life.