

Submission by Mavis Nye to the July 3, 2013 meeting of the Parliamentary
Asbestos Sub-Group

The story of my Mesothelioma is so like that of other sufferers. We call it "Secondary" as I only did my husband's washing; I did not come in contact with the substance at work but my husband did.

Ray has lung damage; scarring but no Mesothelioma. I have Mesothelioma. It is thought due to me having the cancer gene; but really it is unclear why Ray hasn't and I have.

Ray worked at Chatham dockyard as an apprentice, with a break for National Service. In the time of being in the dockyard he worked as a shipwright with the wonder product – asbestos. He was never told it was dangerous, wasn't protected, just worked in overalls and no showers before coming home. He would strip off and change into casual and I would wash his clothes.

I lived a very full and normal life, as I saw the children grow up leave school and go to work, marry; we retired and bought a motorhome and enjoyed life to the full. Then at 68 my life turned around.

I had problems breathing my hands became numb and I was sent for an X-ray. On polling day in the May, I struggled to even walk to vote; I could not breathe. I got back home and had a phone call from the GP who told me a bed had been arranged and would I get there now. I did as I was told and I had 5 litres of fluid drained from my lung which had collapsed. I had a bent diaphragm. And so my journey began of operations, biopsies and chemo. Times of shrinkage and times of growing, a trial that didn't work – so was I on the placebo? I still don't know, as you are not allowed to know that information. Even the doctor isn't, not for three years I believe.

I'm now on 4th line chemo which is very rare in my area so the oncologist could only offer me Cisplatin and Alimta. But, I have become very allergic to those, so I had to go to St. Bart's to find out what I could have. Gemcarbo chemo was offered but I came back for the treatment to my local hospital.

We need a system that is more central, where information is shared. Why does a doctor in the South know more about Mesothelioma than a doctor up North. Why does one hospital know about drugs that can be used and others do not know. I have had to do all my own research; I have been in charge of my disease but I want the doctors to be in charge; to be able to tell me what I need. That doesn't happen, not always.

It's not easy for us, we have a death sentence over us.

We need more money spent on research. Mesothelioma is not the rare cancer that I keep being told – that excuse is very lame. Asbestos damage is lying in so many lungs, hidden but growing into tumours, and there will be more and more cases

diagnosed. The second wave is coming, of people that have done DIY in their younger years and children sat surrounded by asbestos in our schools.

There is so much to look at and I get so frustrated that I see so many trials in the USA, Australia and Europe. When I ask about what is new here there isn't much and they are usually for 1st or 2nd line chemo; I'm now looking for 4th line. Mine is slow growing so my survival has been good. Four years instead of the three months diagnosed at the beginning.

We are supposed to be in Europe so why can't we share the grants and share research and trials to fight this disease. I realise the country that finds a cure will be rich, but not at the cost of patients' lives. Please join together and share. Please look at chemo washes, and cryo where they freeze the tumours; and earlier detection so I could have had a lung out even. I cope with Meso so I could cope without a lung.

All I ask is all treatments be explained in great detail with more options, as far too many times patients are told to go home and enjoy what little time they have left with their families. Do the bucket list in fact.

The way we have found out so much is through Facebook where we have joined together around the world and seek info from each other, to help and cry with each other as each patient dies. There is no other Cancer that has this personal back-up. Thank you for listening to me – we were all given months and then we gained years; and we should be grateful to our doctors and nurses that we are stretching the boundaries. We are the pioneers and now we are teaching the medical profession. One day there will be a cure and we will have played a big part. But I have been robbed of a future, and because my exposure was before 1964 I can't even make a claim for that fact.