

AAW/UK is a patient advice / help line. The founder members have all lost a loved one to Mesothelioma at relatively young ages i.e. 51 – 60 years. As Commentators we would like to make the following points

- This is younger than that quoted by Dr. Meurs in his letter dated 06/05/05. We believe that this trend will continue as more people are diagnosed. We feel this to be relevant in the use of Pemetrexed as the outcome might be better at a younger age of presentation.
- We know that the collection of statistics in Wales does not reflect the true incidence of mesothelioma. Asbestos related diseases in Wales is not recorded under one heading. Mesothelioma comes under Cancer and Asbestosis under lung disease. Also, there is no one heading which collates Occupational health Diseases. Therefore who actually knows the true epidemiology figures relating to Mesothelioma. Regarding the health economics, we are alarmed that this might impact on the availability and access of a drug that is found to be useful. This has impact for the medical management of the patient as Meso patients are somewhat 'unique' in the symptoms and problems they present with.
- To date there is no standardised Clinical pathway for the management of such patients. Management tends to be decided by whatever consultant happens to be looking after you. Indeed there are no NICE guidelines for this disease either. NICE have only produced guidelines for lung cancer from other causes.
- We feel that where a drug is indicated as being 'helpful' in chemo naïve or unresectable cases it should be made available on **compassionate** grounds and also used for Peritoneal Mesothelioma cases.
- Not all patients can gain access to Clinical trials, indeed there has until now been a dearth of such trials in the UK. Our experience indicates that patients would be happy to participate in such trials knowing that if it has no benefit for them at least they have tried everything available, and anyway, it may help others in the future. Also, the patient is managed and monitored more closely whilst in such trials. Participation however it is at the discretion of their Physician whether they are put forward, in our experience very few patients seem to be offered the opportunity. Could it be that the additional work incurred by the staff combined with limited resources is deemed to be a 'waste' as the patient is going to die anyway?
- On Quality of life issues page 3 Appendix A, we make the following comments:

There seems to be very little Qualitative research into QoL issues and no consideration is given in the health economics to 'suffering' incurred both by the patient and carer/ family. The psychological impact of being given a 'death sentence' in the form of a diagnosis when the disease has been incurred through doing a job, we think is different to that of the general background risk of developing cancer. There is not enough research being done into such issues. Also, not enough emphasis is made to the patient and family by the medical profession that 'symptom control' is also a 'choice' or pathway they can take. This may even help eliminate some of the problems experienced in accessing and managing pain control. These should be considerations for inclusion in any future guidelines.

Many patients are told that no effective treatment is available and are told to go home and put their affairs in order (personal experience ). If there is a drug available that has been shown to be effective patients should be given all the information in order to make an informed a choice and should have equal access to that drug irrespective of cost.

