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NICE

COMMENTATORS ASBESTOS AWARENESS WALES / UK

Having read the Assessment Report we feel that we are only able to comment upon the Quality of Life issues. The points we will comment upon are listed below.

MPM should no longer be thought of as a disease of the older generation as more men are being diagnosed at an earlier age. One Founder Member of AAW/UK lost her husband prematurely at the age of fifty one. Diagnosis at an earlier age seems to be an increasing trend.

Life expectancy and pain management is uppermost in the minds of all patients. Sadly not all patients can be pain free with the existing palliative care and pain relief services regime.

There is no current Nationally agreed Clinical Pathway for the management of patients diagnosed with MPM. Therefore the exact nature of the care given, varies throughout the country and is frequently not well documented. As the Assessment report states data from other forms of lung cancer tend to be applied in MPM. Sadly time is not on the patients' side. This lack of detail makes comparison across any trials being conducted almost impossible.

How can it possibly be said that the cost of a new therapy may detract from existing resources? As already stated there is no medical pathway for MPM patients and little evidence to assess effectiveness of palliative care. Few studies exist at present that describe 'Best Practice' nor is there any Evidence Base documentation that describes best management, so existing cost to each patient is unknown.

Little government money is spent on research into MPM so how can the quality of life for those affected be improved? Choices that were unavailable even four years ago can now be made available if Pemetrexed plus Cisplatin is approved for MPM sufferers. Obviously side effects have to be considered but surely it must be the choice of the patient when presented with all the facts of this treatment to decide the next step. The physical and emotional cost to sufferers and their families is rarely mentioned in such studies but we feel this should also be a consideration in the Assessment process and be acknowledged.

No one should ever be denied Hope.