

## **Appraisal of pemetrexed disodium for the treatment of malignant Mesothelioma**

**Liz Darlison**

**Personal Statement**

I qualified as a registered nurse in 1986. I spent several years working as a ward manager on a busy acute respiratory ward. In 2000 I took up the post of Lung Cancer Nurse Specialist and began to develop a particular interest in Mesothelioma. I am currently practising as a consultant nurse specialising in Mesothelioma. I am responsible for the development of the National Macmillan Mesothelioma Resource Centre (Mesothelioma UK).

### **Background information about Mesothelioma UK**

In June 1999 in response to the increasing incidence of malignant Mesothelioma Macmillan Nurse Mavis Robinson set up a national Mesothelioma helpline at the Cookridge Hospital in Leeds. It was funded by Macmillan Cancer Relief. The funding ceased in 2002.

As well as producing and distributing patient information Mavis set up a network of approximately 60 specialist nurses across the U.K. They were provided with training and resources to develop their Mesothelioma knowledge and skills.

The idea for developing a national resource centre for Mesothelioma was therefore born out of the achievements made by Mavis. Macmillan were keen to continue their support and following national negotiations between Macmillan Cancer Relief, clinical staff and management Mesothelioma UK was established within the University Hospitals of Leicester.

### **Purpose of the NMMRC**

To provide impartial, up to date information relating to malignant Mesothelioma for all Mesothelioma patients and their carers. To promote the development of specialist nursing practice and facilitate associated nursing research. To promote the highest possible standards of care and improve the outcome for patients with Mesothelioma in the U.K.

### **Specifically Mesothelioma UK provides: -**

A free phone help line.

A website [www.mesothelioma.uk.com](http://www.mesothelioma.uk.com)

A range of mesothelioma patient information

Co-ordinate in collaboration with National Lung Cancer Forum for Nurses, a network of nurse specialists specifically interested in Mesothelioma.

National Mesothelioma workshops/meetings.

## Management of Mesothelioma UK

Mesothelioma UK is hosted by the University Hospitals of Leicester and is subject to their usual management policies and procedures.

A steering committee (membership below) oversees the development of the service, sets objectives and monitors performance.

### Chair

Jeremy Steele      Consultant Oncologist      St Bartholomew's Hospital

### Vice-Chair

Mick Peake      Lead Clinician for Lung Cancer      Glenfield Hospital

### Members

Liz Darlison	Nurse Consultant - NMMRC	Glenfield Hospital
Dawn Mckinley	Operational Manager - NMMRC	Glenfield Hospital
Tracey Stace	Clerical Assistant – NMMRC	Glenfield Hospital
Michael Snee	Consultant Clinical Oncologist	Cookridge Hospital
Martin Muers	Consultant Physician	The Leeds General Infirmary
Tom Treasure	Professor of Cardiothoracic Surgery	Guy's Hospital
Erica Lowry	Macmillan CNS – Mesothelioma	Papworth Hospital
Sally Moore	Lung Cancer Nurse Specialist	Guy's Hospital
Helen Clayson	Honorary Research Fellow	Hospice of St Mary of Furness
Ann Lee	Relative/Carer Representative	Leeds
Jane Rudge	Service Development Manager	Macmillan Cancer Relief

## Information Helpline

The national freephone helpline 0800 169 2409 has been available since 13 September 2004 and is open and operated Monday - Friday 9:30 am to 3:00 pm. In the first year of being open over 600 calls were received.

## Website - [www.mesothelioma.uk.com](http://www.mesothelioma.uk.com)

The website was made available on the WorldWideWeb on 9 February 2005 and receives an average 30 hits per day.

## Professional representation and membership

Royal College of Nursing	Member.
British Thoracic Oncology Group	Nurse Representative on Steering Committee.
National Institute of Clinical Excellence	Technical appraisal committee member.
Medical Research Council (MSO1)	Trial Steering Group member.
Institute of Cancer Research (MARS)	Trial Management Group member.
National Lung cancer Nurses Forum	Vice-Chair.

U.K. Lung Cancer Coalition Nurse representative.

Department of Health Lung Cancer and Mesothelioma Advisory Group Nurse representative.

### **Presentations & Lectures**

Role of the Lung Cancer Nurse Specialist	Respiratory & Education Resource Centre	June 2001
Lung Cancer Workshop	Cancer Services Collaborative Tri-regional Conference London	June 2001
Mesothelioma	2 <sup>nd</sup> International Respiratory Nurses Conference	Oct 2001
Managing Breathlessness	North-west Leicester PCT Training Day.	May 2002
Mesothelioma – Preparing to meet the challenge.	Scottish Nurses Lung Cancer Interest Group	June 2002
Mesothelioma – The Silent Epidemic	Industry Sponsored Mesothelioma Meeting Sheffield	Oct 2002
Lung Cancer – Aetiology, Epidemiology and Treatment	Leicester University Medical School (250+ students)	Nov 2003
Mesothelioma	West Midlands Lung Cancer Nurses Forum	Dec 2003
Mesothelioma A Challenge for the Lung CNS	The Silent Epidemic Irwin Mitchell conference London	May 2004
Nursing Issues in Caring for People with Mesothelioma	Guy's & St Thomas's Focus on Pleural Disease	Sep 2004

Mesothelioma UK	North East Lung Cancer Nurses Group, Durham.	Sep 2004
Supporting People with Mesothelioma	Lilly Oncology (London) Practical Management of Thoracic Cancer	Sep 2004
Nurse Led Services	Respiratory Matters RCN Conference	Oct 2004
Mesothelioma & the Role of The Lung Cancer Nurse Specialist	Northern Cancer Network	Feb 2005
Update on Mesothelioma UK	Mesothelioma Summit	March 2005
Mesothelioma/Legal Aspects of Mesothelioma	Iain Rennie Hospice	May 2005
Role of Lung Cancer Nurse Consultant	Leicestershire Palliative Care Group	May 2005
Mesothelioma UK One Year On	Mesothelioma The Silent Epidemic Irwin Mitchell conference London	May 2005
Asbestos Implications for Nurses	The School of Cancer Nursing & Rehab. Lung Cancer Module The Royal Marsden Hospital	May 2005
Mesothelioma	The School of Cancer Nursing & Rehab. Lung Cancer Module The Royal Marsden Hospital	May 2005
Mesothelioma the Issues – From a Nursing Perspective	National Cancer Network Development Day	Oct 2005
Developing Mesothelioma Nurse Consultant Post	Leicestershire Cancer Network Sharing Good Practice Day	Oct 2005
Mesothelioma UK	Derbyshire Asbestos Support Group & AMICUS	Nov 2005

	Respiratory Diseases Seminar	
The Ways and Means of Supporting People with Thoracic Cancer	Lilly Oncology (London) Practical Management of Thoracic Cancer	Nov 2005
Macmillan Mesothelioma UK + Role of the Consultant Nurse	Wales Lung CNS conference	Nov 2005
Mesothelioma UK Update	NLCFN Annual Conference	Dec 2005
Should Patients with Inoperable Lung Cancer + Poorer Performance Status (2,3,4) be Considered for Palliative Chemotherapy	British Thoracic Society winter meeting	Dec 2005

### **Pemetrexed.**

There is a huge variation in the treatment offered to patients with malignant pleural Mesothelioma (MPM). This variation is not usually due to appropriateness of treatment based on the patient's performance status, age, other health problems, and disease stage and cell type. Unfortunately the lack of evidence regarding treatment results in a greater variation in the opinion of specialists and perhaps an increased amount of nihilism in non-specialists. Patients and their carers are caught in the middle of all of this uncertainty and yet are expected to contribute to pivotal decisions regarding their treatment.

I am not qualified to comment on the benefits or otherwise of pemetrexed. However anything that contributes to the body of evidence and adds clarity to the options available for treating patients with MPM is beneficial. I understand from oncology colleagues that whilst it is difficult to decide whether pemetrexed is any better than other agents in treating MPM it would appear to be better tolerated with patients experiencing less toxicity. Given the limited life expectancy and severe symptoms often associated with Mesothelioma anything that can potentially enhance or prevent a greater deterioration in quality of life irrespective of the cost is worth consideration.

Currently I am aware of several patients across the UK who are battling to access pemetrexed locally. Some have been successful, others travel a great distance to access it in another part of the country that is able to prescribe it.

Others settle for an alternative treatment that is available locally despite not being licensed to treat MPM. These patients are already 'victims of our time' given that their disease, in a majority of circumstances, has resulted from exposure to asbestos. Continuing to not allow access to a licensed medication where the health care team and patients opt to have it, adds greatly to the burden of their disease and reinforces their status as a victim.