

**CareSearch Project**  
**Research Studies Register: Registration Proforma**

**0037**

**Study Title: A very public death – exploring the needs of a person dying of mesothelioma or asbestos related lung disease**

**Brief description of the study:**

**Background**

It is anticipated that cases of mesothelioma will continue to rise significantly over the next fifteen years with power station workers having a risk second only to asbestos mill workers. People with mesothelioma and asbestos-related lung cancer (M/ARLC) often have had past experience of close family, friends and colleagues dying of the same disease. Mesothelioma responds poorly to treatment and is always fatal, yet there have been few studies related to the palliative care needs of this diagnostic group and none focussing on the Latrobe Valley.

**Design**

The study was a descriptive exploratory case study, undertaken to highlight the needs of people dying of mesothelioma and their families in the Latrobe Valley. Data included in-depth interviews with 13 people; those suffering from M/ARLC, carers and stakeholders. In addition, media reports, local authority and employer reports and historical data were content analysed. Data analysis used the constant comparative method to identify common themes and issues.

**Key Findings**

The findings indicate that those with M/ARLC and their families find diagnosis and treatment phase of the illness is filled with unpredictability and fear. Although there are some cancer treatment and legal services locally, people with M/ARLC are often required to travel to metropolitan services for care and advice. They have a strong desire to die at home but their care is often complicated by issues of rurality, isolation and late referral to palliative care services.

**Recommendations**

- Investigate innovative models of care to improve communication and continuity of care
- Secure funding for continuity of psychological support
- Investigate barriers and enablers to local health and legal service provision
- Comprehensive education strategy for health providers and public
- Develop strategies to prevent and manage volunteer and professional burnout

**Study Methodology: (Please mark with an x which type of study methodology)**

	Epidemiology
<b>x</b>	<b>Health Services / Health Economics / Quality Improvement</b>
<b>x</b>	<b>Qualitative, Observational or Descriptive</b>
	Mixed Method
	Systematic Review
	Intervention: RCT
	Intervention: Comparative or cohort study
	Intervention: Case series

<b>Project details:</b>						
Funding source (Optional): Monash University Collaboration grant						
Has the study received ethics approval?	<input checked="" type="checkbox"/>	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Not applicable
Project starting date: 26.10.06						
Project completion date: 15.12.08						
Multi site:	<input type="checkbox"/>	Yes	<input checked="" type="checkbox"/>	No	<input type="checkbox"/>	Not applicable
<b>RESEARCHERS</b>						
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Investigator F (Name)	Ms Vicki Hamilton					
Investigator G (Name)	Ms Barbara Cass					
<b>Associated publications / reports: Final report:</b>						
<a href="http://www.med.monash.edu.au/nursing/research/reports/a-very-public-death-report.pdf">http://www.med.monash.edu.au/nursing/research/reports/a-very-public-death-report.pdf</a>						
Lee,S., O'Connor, M., Chapman, Y., Hamilton, V. & Francis, K., (2009). <a href="#">Very Public Death: Dying of Mesothelioma and Asbestos-Related Lung Cancer (M/ARLC) in the Latrobe Valley</a> . <i>The International Electronic Journal of Rural and Remote Health</i> . 9 (on-line) 1183. Available from: <a href="http://www.rrh.org.au">http://www.rrh.org.au</a>						
<b>Topics: Cancer, General assessment issues and goals of care, caregiver</b>						