

## ORIGINAL RESEARCH

# A very public death: dying of mesothelioma and asbestos-related lung cancer (M/ARLC) in the Latrobe Valley, Victoria, Australia

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**A very public death: dying of mesothelioma and asbestos-related lung cancer (M/ARLC) in the Latrobe Valley, Victoria, Australia**

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## ABSTRACT

**Introduction:** It is anticipated that in Australia the number of cases of mesothelioma will continue to rise significantly over the next 15 years with power station workers having a risk second only to asbestos mill workers. Mesothelioma responds poorly to treatment and is almost 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, Victoria, Australia. The aims of this pilot study were to identify common issues and to explore the needs and experiences of people with mesothelioma and asbestos-related lung cancer (M/ARLC), their carers, and service providers in the Latrobe Valley community, in particular in relation to palliative care.

**Methods:** The study employed a case study design using in-depth interviews, media reports, local authority and employer reports and historical data, which were content analysed. The constant comparative method was used to identify common themes and issues.

**Results:** The Latrobe Valley is the fourth largest regional area in Victoria. The electricity industry and brown coal mining at the town of Yallourn were the primary industries. Former power workers are contracting mesothelioma at a rate seven times the national average. A total of 13 participants from the Latrobe Valley were interviewed, comprising five key stakeholders who were local legal and healthcare providers; two people who had been diagnosed with mesothelioma; and six family carers. Most people with M/ARLC in the Latrobe Valley are older males who were employed by the electricity and related industries, while their carers



are mostly female wives and daughters. There were three major themes identified in the data: illness experience; carer and family roles; and services and service gaps. The results indicated that those with M/ARLC and their families experience diagnosis and treatment as being filled with unpredictability and fear. The older males with M/ARLC were characterised as stoic and reluctant to seek help, contributing to a delayed diagnosis. However, their rural health services compounded these delays because of the unpredictability of health professional availability. 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. The effort and time required to seek compensation at a time of declining health was particularly burdensome. Participants expressed the tension between feelings of loyalty to their employers and anger at the perceived betrayal of the same employers, who were reported to have ignored asbestos warnings. Access to palliative care was delayed by a discomfort associated with acknowledgement of dying and resulted in poor symptom control and a lack of support to significantly burdened carers. People with M/ARLC have a strong desire to die at home but issues of rurality, isolation and late referral to palliative care services often complicate their care.

**Conclusions:** This pilot study explored the needs of people with M/ARLC in the Latrobe Valley and the results indicated that their experience is complicated by unpredictability, lack of information and the rural location. The study recommended that innovative models of care be investigated to improve communication and continuity of care in the Latrobe Valley community, in addition to the barriers and enablers to local health and legal service provision. Further, the study indicates that a comprehensive education strategy for local health providers and community members, and strategies to prevent and manage volunteer and health professional burnout are needed.

**Key words:** asbestos, compensation, lung cancer, mesothelioma, palliative care, rural health.

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## Introduction

Asbestos was used extensively from the 1800s in industrial applications and as early as the 1900s, workers in the asbestos industry were reported to be dying of respiratory diseases. However it was many years before the publicity surrounding the risk to workers of asbestos exposure resulted in the removal of asbestos from industry.

Asbestos related lung disease can take many years to develop following exposure and can manifest in benign or malignant forms<sup>1</sup>. Mesothelioma is a cancer of the cells lining the lungs and abdominal cavity. It has been strongly linked to asbestos, is poorly responsive to treatment and is almost always fatal. Asbestos related lung cancer (ARLC) causes similar symptoms and is treated similarly to lung cancer in non-asbestos-exposed individuals<sup>2</sup>.

Although mesothelioma and asbestos related lung cancer (M/ARLC) is a worldwide health issue, the focus for this

study was the Latrobe Valley, Victoria, Australia. The Latrobe Valley is located at the gateway to the Gippsland area in the south east of the state of Victoria in Australia. The population of 72 000 residents living in the Latrobe Valley regional area<sup>3</sup> grew around the development of the electricity industry and the mining of brown coal at the town of Yallourn. Power station workers were exposed to asbestos during construction of the power stations, as well as in the building of their own homes<sup>4</sup>. Former power workers in the Latrobe Valley are reported to be contracting mesothelioma at a rate seven times the national average<sup>5</sup>.

### *Literature review*

The aim of the literature review for this study was to determine the issues experienced by people with M/ARLC. The literature review identified scholarly work relevant to the study, as well as reporting attitudes and opinions related to the study apparent in media articles, reports and historical literature. The literature selected for the review focused on the perspectives of people with M/ARLC and their issues



associated with the experience of diagnosis, legal issues associated with compensation and the search for curative treatments. There was little published information regarding the impact, experiences and needs of people diagnosed with M/ARLC and their families, and a lack of Australian studies, an observation supported by Hawley et al<sup>6</sup>.

Haigh, in his book 'Asbestos House', detailed the history of asbestos in Australia, focusing on the James Hardie Company<sup>7</sup>. This company was a broad-based building supply company that provided asbestos products. The book indicated the significant time difference between early reports of apparent asbestos related illness and acknowledgement of the risk among health authorities and the James Hardie Company. The significance of the organisational apathy towards the risk may impact on issues experienced by people who are subsequently diagnosed with mesothelioma<sup>7</sup>. It has been suggested that the pain experienced by those diagnosed with mesothelioma is often complex, and exacerbated by issues such as anger relating to the causative factors of the disease being out of control, and ongoing legal action<sup>8</sup>. The complexity of the pain experienced by those with mesothelioma was confirmed by a multidisciplinary team developed specifically to address the pain issues of people at a hospice in the UK, which found particular issues for people diagnosed with mesothelioma<sup>9</sup>. Despite identifying that people with mesothelioma had significant psychological distress, another study by Clayson, Seymour and Noble also found people with mesothelioma were stoic and more likely to request sedation rather than be involved in psychological strategies to address their distress<sup>10</sup>.

The provision of palliative care services in all settings and the enhancement of continuum of care have demonstrated benefits<sup>11-13</sup>. Palliative Care is defined by the peak Australian organisation Palliative Care Australia as 'specialist care provided for all people living with, and dying from a terminal condition and for whom the primary goal is quality of life'<sup>14</sup>. Preferences for being nursed in the home with twenty-four hour telephone support are shown to be key

components in improving patient and carer satisfaction, according to a study on aspects of cancer<sup>15</sup>.

For some people diagnosed with mesothelioma, the energy and time required for finding out how to navigate the health system can be burdensome when they are already quite ill. An Australian study on developing strategies to meet the needs of people with mesothelioma included assistance in 'navigating the journey'<sup>6</sup> as an important strategy to be addressed in planning for the future. Although this study did not focus specifically on the experience of palliative care for people with mesothelioma, planning for the future would logically include the provision of palliative care. As a result of that study, Hawley and Monk reported that people diagnosed with M/ARLC have two main issues<sup>16</sup>. The first concerned hope for a cure, and the second was a concern regarding the location of their end of life care. The need for respite care is also highlighted to support families in what is referred to as 'the burden of care'.

The literature highlighted the burden for families beyond normal grief reactions of the newly bereaved. This additional burden related to the necessary involvement of the coroner and the autopsy the coroner might recommend, which can impact further on the anxiety and stress of surviving families<sup>17</sup>. In addition, compensation claims can increase the burden of suffering<sup>18</sup>.

The literature review indicated that M/ARLC is likely to cause significant distress in people with the disease and their family and carers, but there is a scarcity of research to inform service provision, particularly in palliative care. Because of its high rate of M/ARLC, the context of the Latrobe Valley gives further weight to the necessity for more research in this area.

## Methods

As there was little research informing the palliative care needs of people with M/ARLC and their families, particularly in the Latrobe Valley, a descriptive case study



method was chosen as a methodology for this project. The case study method consists of a detailed study of a group using multiple data sources, described as an embedded case study design<sup>19</sup>. Case study methods are useful when the context of a situation is complex and central to the study and where multiple perspectives need to be recognised, as is the case with this study<sup>20</sup>.

Prior to data collection, the project received approval from the Monash University Standing Committee on Ethics in Research on Humans.

A convenience sampling method was used whereby volunteers responded to advertisements about the research project in local support group newsletters and local media. Stakeholders were identified by the reference group and sent an invitation to participate by mail.

In-depth interviews of people who have been diagnosed with M/ARLC, family members and other key stakeholders, historical literature and media reports were used as data sources. In addition, field notes were taken during the interviews to provide additional insight into the context of the data.

The recorded interviews were de-identified and transcribed verbatim. On some occasions, follow up telephone calls and email communication were undertaken to clarify particular points in the interview transcript.

The transcripts were analysed using the constant comparison technique<sup>21</sup>. This technique involved line by line comparison of data and the generation of common concepts. Concepts were combined and reduced to common themes and sub-themes. Data collection continued until saturation was achieved; that is, that no new concepts were arising from the participants and the data was being repeated<sup>21</sup>. The field notes, media and historical reports were used as analytical memos<sup>21,22</sup> to deepen the researchers' understanding of the context of concepts arising from the analysis of the transcribed interviews. To address trustworthiness of the data analysis, the transcripts were read by each member of the

research team and the analytical concepts were discussed and verified during their development.

## Results

A total of 13 participants were interviewed, comprising five key stakeholders who were local legal and healthcare providers, two people who had been diagnosed with mesothelioma and six family carers.

The three major themes developed from the data were related to the illness experience, carer and family roles, and services and service gaps.

### *Illness experience*

Although there was awareness of the risks of M/ARLC in those living and working in the region, it seemed that the initial diagnosis was accompanied by shock for most people. Despite the local publicity about asbestos related illnesses, there was confusion about the diagnosis of mesothelioma. One stakeholder commented that:

*...sometimes the doctors will refer to them as shadowing on the lungs and the people get a terrible fright because they know they've been exposed to asbestos, they read a lot about terminal mesothelioma and their first thought is, oh Christ I'm going to die and they'll come and get advice and I'll say, well you know, you ain't going to die, it's only a marker...(ST1)*

There were often delays in the diagnosis compounded by transient, inexperienced, part time or unfamiliar health professionals. This created a necessity for patients to navigate an unfamiliar health system themselves. Becoming unwell in the holiday period, in a rural location caused a significant delay in diagnosis for one participant's partner:

*He was there [in the local hospital] for seventeen days ..., the local lung specialist was away and, a lot of*



*them were on holidays ...you know, very, very traumatic time. (C5)*

One carer commented on difficulties in establishing a relationship with a GP, ‘...none of us ever went to doctors because we were never sick’ (C3). Additional trauma resulted when they developed a rapport with a young GP on a rural rotation who left the area after the initial diagnosis had been made.

It was not possible to predict if one would get M/ARLC or how long one might survive it. In stories about themselves and others, the participants told how they had watched one worker after another succumb to M/ARLC, where others escaped. Whereas one man in the community had survived for years following the diagnosis of mesothelioma, others had lived only months. It was acknowledged by participants that treatment options only have the possibility of extending lives for a short period of time. In addition, treatment of M/ARLC involved substantial side-effects and potential costs associated with travelling for treatment. Outpatient visits and admission to metropolitan hospitals were strenuous for some, impacting on the patient and their family and decision-making about treatments.

Many participants talked of those who lived with fear that every cough, snuffle or pain might indicate they had the dreaded M/ARLC. Because they stayed in the community in which they had been exposed, there was a constant reminder of M/ARLC due to a significant number of friends being diagnosed with asbestos related disease, dying and their own attendance at funerals.

*There was always someone going [dying] ... You never went to any of the funerals, because it was too many ... it gets to you ... in this area, too many, there are too many, too many. Yeah so when they see all the gang going you know, I don't know, there's about thirty or so in the gang and you're practically the only one left ... it gets to you, that's why I never went to any of the funerals. (C1)*

They were also conscious that for years they had been kept in ignorance of the risk related to working with asbestos because in the early days their employers failed to take the threat seriously. At the same time they were mindful of the danger they had brought to their families. Talk of suicide was not uncommon among those living with the threat of M/ARLC.

*This gentleman did tell people that he was going to commit suicide if he was ever diagnosed with anything more severe than pleural plaques ... he got diagnosed with asbestosis ... he'd watched so many of his workmates pass away with asbestos related disease and he put a sign in the window and he committed suicide ... you know, you can go for 15, 20 years with asbestosis ... (ST2)*

During the illness experience, maintaining family independence was a priority for participants. They described the strong community spirit evident in raising awareness, fighting for compensation and offering assistance to others. This description was in contrast to the stoic older men with M/ARLC who were described as preferring to remain independent and living with their disease almost in isolation of the supports available. Unfortunately this self-imposed isolation was an additional burden on family members.

*You know, he was always in pain ... he was very good, he always kept it covered up. He wasn't one to grizzle. He was very brave actually or silly, one of the two, I don't know. (C1)*

Some had an uneasy feeling related to the legal aspects of the diagnosis. Some participants expressed a dilemma between their loyalty to companies that had given them longstanding employment, and feelings of anger and betrayal towards those same companies who were reported to have chosen to disregard warnings.

*... I loved my job and really I don't point any fingers at anybody I worked with because they were all just*





*employees ... I've got what I've got and there's nothing I can really do about it ... like there's other people that have got the same problem as I have, some have already gone, there's others waiting to go, we're all in the one boat, so I just look at it as well, let's get on with it and enjoy what we've got and we'll just take it day by day. (PD2)*

## Carer roles

Those who care for people with M/ARLC face challenges related to the care of the ill person and related to the loss of that person. Most often non-professional carers are family members; however, professional carers such as doctors, nurses and allied health staff also face issues related to caring for those with M/ARLC and their family members. In addition to family and professional carers there are non-professional volunteer carers and supporters of people with M/ARLC and their family members. This study found that all three types of carers experience issues related to their roles.

The losses experienced by family carers were compounded by decisions to move closer to care. One carer explained that '...everything you sort of got, you know, you had to sell and get rid of and that's just how your life progresses ... downwards' (C1). Their burden of care was often complicated by additional care needs of ageing parents, young children or grandchildren. Participants indicated that they were fatigued by their caring roles. One carer indicated that she '... was never rested, [she] was always doing something...' (C1).

The burden of care for family members created a need to talk about their experiences and this need was met by neighbours or friends. The close community of supporters in an environment where M/ARLC is so common meant that some individuals, professional and lay carers bore a significant burden with little or no training or support for themselves.

*She [a friend], she just about did everything because she'd worked in [a health care facility] so she kept an*

*eye on him and she was quite in tune with anything that happened with him, she'd heard of just little things that helped when she was working and so she knew how to look after him, she was so excellent, I did a little bit, but that was really under her instruction ... (C5)*

Young health professionals in general practice were particularly vulnerable. The GP mentioned earlier who was on rural placement was particularly affected by that patient's case and the sense of isolation and responsibility she experienced in rural practice. The family carer explained that:

*... she came out here the day she was leaving and brought us a box of chocolates and she was in tears and she said, I'm never going to work in public practice again, I just can't do it, she said, I can't face what I see ... in a hospital you can hand people onto someone else and they deal with and she said, in general practice you have to deal with it all yourself. (C3)*

Non-professional carers and supporters may be volunteers in local services or, more often, friends of the people with M/ARLC or their family members. Participants identified that for non-professional supporters, there was an emotional cost associated with their role for which counselling was essential. One explained that:

*I felt that I needed to have some sort of personal support myself ... I feel it's appropriate for the things that you're doing and for your own health ... (ST2)*

The experience of caring led carers to an understanding of the risks of asbestos related disease and the desire to improve knowledge in the community. Some carers became supporters of others in the community by volunteering in the support group. In this group they provide advocacy regarding asbestos in the community, make home visits and offer telephone support for people affected by M/ARLC.



## Services and service gaps

The Latrobe Valley has a new cancer treatment centre at the town of Traralgon and various community services, including a community palliative care service. Nevertheless, many people did not use local services, instead travelling to Melbourne for their surgery and cancer treatment.

*... we had an appointment in at the [city hospital] to see a thoracic specialist and a fortnight later he was in hospital and had the operation to find it and they were only going to put a little camera in, that they stick down the lung, but [my husband's lungs] were already too stuck down [damaged by the cancer] so, so, you know, very, very traumatic time. (C5)*

The lack of holistic care provided by health professionals during the diagnostic and treatment phases of illness meant there was a sense of needing to navigate the system on ones own to get help. Referrals to palliative care services occurred late in the illness:

*... my only regret was that we didn't use their expertise for pain relief earlier. A, I didn't know how much pain he was in and B, I thought like most people do, that palliative care's only for the final stages. (C3)*

One carer described palliative care nurses as 'the angels of death'. There was some concern about the lack of bereavement services and that treatment and other decisions were made on the basis of distance to travel: 'I don't think I'd like to be a burden on anybody having to drop everything and run me to Melbourne every time...' (PD2).

Despite their awareness and acceptance of the risks of living and working with asbestos, when it came to understanding their disease, people with M/ARLC found it difficult to access reliable accurate information. Some used the internet as a resource when information was not provided by their health professionals. One carer described her husband's

search for information as indiscriminate and yielding a large amount of negative information:

*He got on the computer and downloaded everything he could find out ... then we would read the information, wherever he got the information from, we just had all this information about it, so I was quite aware you know, if you read about it and everything was very doom, doom.... (C5)*

## Discussion

The results of this small pilot study indicate that the unpredictability of diagnosis, treatment and care and delays experienced by those with M/ARLC in the Latrobe Valley were significant additional burdens to family carers. These issues of unpredictability and delays, and carer and family burden are further explored in relation to the literature and previous research.

### *Unpredictability and delays*

This study demonstrated that one of the most significant aspects of the experience of M/ARLC is that of its unpredictability. People who have lived and worked in the Latrobe Valley for some years are aware of their history of exposure to asbestos and the link between asbestos and cancer. Despite this awareness, there are still delays in the diagnosis of M/ARLC and shock when it occurs. Particularly in the diagnostic phase, there is a lack of accurate, accessible information on the disease and its treatment. Further, the experience of M/ARLC among friends, relatives and acquaintances creates fear and reluctance to ask for help.

A number of factors may influence the delay in diagnosis for this group. Men, particularly older men, may be more reluctant to seek health professional advice for symptoms due to fear of the potential diagnosis. A study of rural men with prostate cancer found they delayed visiting the doctor because of a belief that ill health might be a sign of weakness<sup>23</sup>. The data from this study indicated the men had



experienced symptoms for weeks to months before attending the doctor. In addition, rural residence may add to a delay in diagnosis because people in rural areas are reported to seek medical appointments less often than those living in urban areas<sup>23</sup>.

Unpredictability is also experienced in the diagnostic and treatment phases of illness due to limited access to medical staff, and available medical staff lacking experience of giving bad news regarding terminal illness. Participants discussed the difficulty of establishing and maintaining relationships with GPs who were often on temporary placement in the area and so moved frequently. These are features of rural environments where there is an acknowledged shortage of specialist doctors, in addition to a lack of GPs<sup>24,25</sup>. For people with M/ARLC and their families, the consequences of these issues are significant. A lack of continuity in relationships with medical staff and lack of access to specialists results in delays in diagnosis and treatment. In addition, there is a lack of accurate information about disease processes, treatment, treatment outcomes and the support services.

Despite the publicity surrounding M/ARLC rates in the Latrobe Valley and the regularity with which the issue appears in local and metropolitan newspapers, participants often reported knowing of people who struggled with symptoms for some time before seeking medical attention and who were then shocked by their diagnosis. During the diagnostic phase, which was often delayed by the lack of timely appointments for tests, results and specialists, people found it difficult to access consistently reliable, honest and accurate information about M/ARLC and its treatment. A reliance on the internet as a source of information is common, despite concerns about searchers knowing how to formulate queries and the quality of the information accessed<sup>26</sup>. Navigation of the Victorian Government Health Information website is difficult. A search of this website revealed many reports on environmental risk and government responses, but little on diagnosis and treatment, and no links to local services<sup>27</sup>.

One of the most active sources of written information about M/ARLC is the local support group, but the group is unfunded and relies entirely on volunteers to provide office staff and support services<sup>28</sup>. At the time of writing the Gippsland Asbestos Related Diseases Support Inc. organisation had been granted funding by WorkSafe Victoria to provide some paid employment. It remains to be seen what impact this will have on the provision of information.

During the treatment phase of illness, people with M/ARLC often spent long hours travelling to the state capital Melbourne for tests and treatments. It is unclear from the data why such procedures were not undertaken locally, other than the procedure was recommended by a Melbourne-based specialist, or that particular treatments were not available locally. Because of the demands of travel on people in precarious health (sometimes on public transport), endurance of significantly burdensome treatment becomes unpredictable. Furthermore, people with M/ARLC and their families appeared to be unclear as to the value of the treatments they were advised to undertake.

Access to palliative care was found to be linked to issues related to the acknowledgement of dying. Despite the fact that M/ARLC is known to be nearly always terminal<sup>2</sup>, referrals for palliative care are not made until late in the trajectory of the disease. Carers in this study indicated that they would have valued the support of the local palliative care service earlier. In addition, problems of uncontrolled pain among those with M/ARLC were identified. Timely referral to palliative care is a problem experienced in other disease groups, and in the same group in other countries. For example, a small phenomenological study in the UK of people with mesothelioma found a lack of attention to the emotional needs of patients and families, and a lack of information provided to them about specialist palliative care services<sup>29</sup>.

Late referral to palliative care services as a result of discomfort in acknowledging that one is dying is an issue prevalent in the literature, including some relatively recent international discussion<sup>30,31</sup>. Arnold suggests that this is the





result of an image problem in palliative care<sup>30</sup>. However, others have argued that rather than an image problem, there are misconceptions in the community, mainly that referral to palliative care means a person is imminently dying and, indeed, many health professionals still regard death as a medical failure<sup>32,33</sup>. Although this latter problem was not identified in this study, late or no referral to palliative care was prevalent among participants. Early referral to palliative care provides the opportunity for thorough assessment of needs and development of relationships essential to assist in the ongoing plan of living well for the person with M/ARLC and their family until death. In addition, these relationships support the family in bereavement.

## *Carer and family burden*

In this study, the carers were identified as carrying a significant burden related to the care and support of people with M/ARLC, and the navigation of the health services. In addition, the burden of care for carers was complicated by living in a rural community, sometimes isolated from the services they needed to access for diagnosis, treatment and legal compensation matters. Further, families were sometimes required to move the family residence to be closer to support from other family members or health services. Selling important assets and moving home was identified as compounding the sense of loss experienced by people with M/ARLC and their families.

As previously identified, family caregivers often receive limited support and are not referred specifically to palliative care supports until late in the illness. Yet one of the core tenants of palliative care is the support of carers<sup>34</sup>. The burden of care for family caregivers of people with terminal illness has been identified in the literature as contributing to above normal levels of psychological distress<sup>35</sup>. In one Scandinavian study, interviews with family caregivers found a core problem to be carer vulnerability. Further, it was found that 'continuing previous activities, hope, keeping control, satisfaction and good support [were] factors which may decrease the caregiver's vulnerability, and may protect against fatigue and burnout'<sup>8</sup>.

In the present study, a further issue identified by participants was their frequent contact with others experiencing the consequences of living and working with asbestos. There was a sense of being overloaded by the constancy of funeral attendance, and the difficult experiences of family and friends, workmates and other acquaintances reported in the newspapers and at community functions. The small community and limited support systems mean that there is a risk of compassion fatigue and burnout among professional and non-professional carers. Burnout and compassion fatigue are recognised phenomena among those who work in palliative care<sup>36</sup>, but also those who have worked with victims of disaster and personal crisis<sup>37,38</sup> and among family carers of those who have suffered stroke<sup>39</sup>. At the time of the study the unfunded, community M/ARLC support group was staffed entirely by a small group of volunteers who provided 24 hour support, and so were particularly at risk of compassion fatigue and burnout.

Although most of the services in the Gippsland Region Palliative Care Consortium note the provision of bereavement services on their website<sup>40</sup>, the funding of bereavement care is limited. The demand for bereavement services in the Gippsland region may not be fully realised because participants identified bereavement support as a need. Further, the particular bereavement support required may be complicated by issues such as compassion fatigue and caregiver burden. In addition, this particular community may have unique bereavement needs due to the reportable nature of asbestos related illness, the process of compensation claims and the experience of multiple bereavements in a single community.

A welcome Federal Government announcement in November 2006 was the development of a Medicare rebate for the specialist services of a clinical psychologist<sup>41</sup>. This initiative has resulted in a part-time psychologist being appointed to work with people referred by a GP as a part of the person's mental health plan. The psychologist works with the voluntary organisation, Gippsland Asbestos Related Diseases Inc. providing face-to-face, group and telephone counselling (Pers Comm, V Hamilton [Gippsland Asbestos



Related Diseases Inc], 2008). Whether this counselling is sufficient to meet the demand of people with M/ARLC and their families and how this service links with the bereavement care provided by palliative care services has yet to be determined.

## ***Limitations***

This pilot study was designed to identify some of the issues related to the care of people in the Latrobe Valley region. The study was limited by a lack of access to people with M/ARLC in the region who were willing and physically able to speak candidly about their experiences to a researcher. As a result, only a small number of people with M/ARLC, carers and others were interviewed; therefore, the findings are only indicative of issues, rather than generalisable to the whole population. Further research is needed to substantiate the issues and strengthen the findings. However, the findings do generate a number of recommendations to guide further investigation.

## ***Recommendations***

A number of recommendations arose from the study. The first recommendation includes the investigation and improvement of access to and coordination of services. Second, improvement of access to information about M/ARLC and its treatment is recommended. Third, there should be improvement in the support available to service providers.

Appropriate integrated models of care should be investigated that would provide a communication strategy between people with M/ARLC, their families, health services and the Gippsland Asbestos Related Diseases Support Inc group (eg nurse practitioner or case management roles). Such a model of care should assist people with M/ARLC and their families to navigate the health care and support systems available in the Latrobe Valley to ensure timely referrals and to maximise use of local facilities. A similar model has been recommended to meet the needs of people with motor neurone disease in Victoria<sup>42</sup>.

The particular barriers and enablers to comprehensive legal, diagnostic and treatment services for people in the Latrobe Valley should be investigated to determine the factors that cause people to seek these services outside the region.

A funded information strategy about M/ARLC, diagnosis, treatment, local health, support and legal services and processes should be undertaken to provide an up-to-date, accessible and accurate resource for people in the community.

A comprehensive educational strategy on M/ARLC, its diagnosis and treatment, patient-provider communication and end-of-life care planning should be developed and implemented to equip health professionals and the community to manage these elements of care.

Finally, the support of volunteers and healthcare providers should be investigated to ensure proactive strategies are implemented to address the potential for burnout and compassion fatigue.

## **Conclusion**

This pilot study identified some common issues and needs of people with M/ARLC and their families, who are living in the Latrobe Valley. The rates of M/ARLC among those living in the Latrobe Valley who have worked in the power or construction industries are significantly greater than for other populations and, therefore, most people know of the experience of others with the disease. Little research had been conducted on the experience of having M/ARLC, particularly related to their palliative care needs.

A small number of people with M/ARLC, carers and stakeholders were interviewed to ascertain their experiences of diagnosis, treatment and palliative care. The themes developed indicate that the experience of M/ARLC in the Latrobe Valley is complicated by unpredictability, causing delays in diagnosis and treatment, late referral to palliative care and a high burden of care imposed on family,



professional and non-professional carers. Recommendations have been made for further investigation of models of service that will assist people navigate the systems, and provide funded emotional support, education and staff support.

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