

**Work and Health in the
Latrobe Valley:
Community Perspectives
on Asbestos Issues**

FINAL REPORT

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1

Introduction

Australia, like many other countries around the world, is currently experiencing an asbestos disease epidemic due to exposures in past decades [1–3]. The International Labour Organisation estimates that there are between 100,000 and 140,000 deaths worldwide per year from asbestos-related cancers [4]. In Australia, the current asbestos disease burden is most dramatically apparent in the steeply rising incidence of mesothelioma over the past twenty years, which is not expected to peak until sometime between 2010–20 [1]. The number of people affected by the two other main asbestos diseases, asbestosis and lung cancer, is harder to track. This is because there has been a lack of systematic recording of asbestosis as well as an under-diagnosis of the disease, and because asbestos is but one of several known causes of lung cancer. On the basis of the best available evidence, asbestos diseases are estimated to have been wholly or partly responsible for ~25,000 deaths in Australia up to 2001, with an estimated future burden of 10,000 more mesotheliomas and 20,000 more lung cancers [5]. In short, asbestos disease is a serious public health problem in Australia and internationally, and is deserving of a commensurate public health response.

Current responses to asbestos disease epidemics in Australia and internationally are dominated by medical, scientific, legal and government perspectives. The voices and perspectives of those most directly affected—exposed and diseased workers, their families and communities—are, however, relatively rarely heard [6]. While there are some valuable accounts of the lived experiences of people affected through occupational exposures [7–9], situations in which the public is put at risk through environmental exposure seem to garner far greater political attention and sympathy (such as in the widely publicised story of Libby, Montana, in the USA [10]).

The vast majority of asbestos disease, however, is work-related and occurs in local or regional epidemics—in the communities surrounding shipyards, train yards, power stations, mills, and other current and past industrial centres and settings [6–9, 11–15]. Thus, asbestos disease also needs to be studied and understood at the community level. Yet there has been little research on community perspectives on how best to understand and address the current asbestos disease epidemic. This suggests that community participation in the development of responses to asbestos disease and related issues—ranging from social and emotional impacts, to early detection programs, to support and healthcare services, and more—is an under-recognised and under-utilised resource.

This project was developed to explore these issues in the Latrobe Valley of eastern Victoria, a community that has been seriously affected by asbestos disease. Specifically, our aims were to determine:

1. How people in the community view asbestos issues; and
2. What people in the community think could or should be done about those issues.

We believe that this study will be valuable both locally and globally. Locally, it should serve to amplify and strengthen community voices, and enable them to have a greater influence on the dominant and controlling medical, scientific, legal and government views in developing responses to asbestos issues. In this regard, the goal is to summarise and convey community perspectives to other relevant stakeholder groups. Secondly, this study was designed as a first step towards the development of collaborative community-based intervention projects to address asbestos issues in the Latrobe Valley. In this regard, it was consciously designed to build a foundation of mutual understanding and respect between the researchers and the community from which collaborative intervention projects could be launched. This approach to research is supported by the growing awareness among public health researchers and professionals of the need to work *with* rather than *on* communities to improve public health [16–18]. Accordingly, our research is collaborative and participatory, and seeks to integrate public health expertise with community views, and build ways forward that take both views fully into account [19, 20]. Finally, this Latrobe Valley study is a microcosm of the broader Australian and international story. It will provide insights on the perspectives of those most affected by asbestos issues, how such people and their views can be better integrated into current responses, and how their insights and participation can contribute to more comprehensive public health responses to this global problem.

2

Community Context

The State Electricity Commission of Victoria (SEC) was established in the 1920s to supply Victoria's growing power needs. The engine of the SEC was a set of coal-fired power stations and associated industries located in the Latrobe Valley, 160 km to the east of Melbourne. From 1931 through to the 1980s, the SEC directly employed a total of roughly 140,000 people (excluding contractors) [21, 22]. In 1994, however, the SEC was privatised and sold as separate power companies to American and British interests.

The first SEC power station opened in 1924, with several power stations and associated facilities built subsequently. Because of its natural heat- and corrosion-resistant properties, asbestos was used widely in the construction of the power stations—for insulation and gasket materials for piping, as well as for roofing, walls and other purposes. Widespread use of asbestos led to the current epidemic of asbestos disease in the Latrobe Valley. A 2001 report by the State health department found that the Latrobe Valley had the highest rates of mesothelioma of all municipalities in the State for the period 1986–1998 [23]. Men in the Latrobe Valley experienced 3.3 times the State average incidence of mesothelioma, and had 4.6 times the expected rate of mortality from mesothelioma. A more recent study commissioned by the Victorian State government in 2001 also found high mesothelioma incidence (seven times the national average) as well as asbestos – associated excesses of lung cancer among a small cohort of former SEC workers (~3600 employees) who had participated in the SEC's Lung Function Program in the early 1980s [22]. Estimates based on the national Mesothelioma Register indicate that power station workers exposed thirty to fifty years ago (in Victoria and elsewhere in Australia) have the second highest lifetime mesothelioma risk at 11.8 per cent (~one in eight), surpassed only by those who worked in the infamous mines or mills of Wittenoom in Western Australia (16.6 per cent) [24, 25].

In summary, the Latrobe Valley community has been hard hit by asbestos disease, with the mesothelioma burden outlined above topped by roughly twice the number of asbestos-related lung cancers [23, 24] and an indeterminate number of asbestosis cases. This has been substantiated by epidemiologic study, and also by increasing community concern and activity, and corresponding print, radio and television media coverage of the issues.

3

Methods

There are many levels of ‘community’ involved in, and affected by, asbestos disease and related issues in the Latrobe Valley. In this study, we focused on those people in the community who have been most directly affected by asbestos issues because their views are particularly pertinent. We defined those most directly affected as including former SEC workers with past exposures who are at risk of asbestos disease, former SEC workers with asbestos disease, the families of such workers, and their current and former advocates—community-based asbestos support groups and trade unions. The views of many other groups in the community are also relevant (e.g., current and former employers, healthcare providers, clergy, members of the legal profession, various levels of government, and the media). These groups could be the subject of further research in order to build a broader picture of community views, but feasibility considerations limited our focus in this study to the core groups most directly affected.

3.1 Recruitment and Sampling

Former SEC workers (some with asbestos-related disease, some with past exposure) were recruited through contact with local trade union representatives and a local asbestos disease support group. Family members were recruited through the same networks. Using a snowball sampling strategy, further participants were contacted after we completed our initial interviews.

Twenty-nine interviews were conducted with people who have lived and worked in the Latrobe Valley (nineteen men and ten women). Most were long-term residents (thirty years plus), although one was a contractor now living in Melbourne who had previously worked in the Valley. Sixteen ex-SEC workers were interviewed, six of whom have asbestos-related diseases (two with pleural plaques, four with asbestosis). This included a group interview with five ex-SEC workers presently employed in the Latrobe Valley power industry. Most current and former workers have worked in the power industry from their early twenties, and interviews were conducted with people employed from the 1950s to the present.

Interviews were also conducted with six people who had lost relatives through asbestos-related illnesses, as well as seven community members involved in asbestos support or advocacy in the Valley—two trade union representatives and five members of asbestos support and advocacy groups (two from Latrobe Asbestos Disease Support [LADS] and three from Gippsland Asbestos Related Disease Support [GARDS]).

3.2 Data Collection

Before the start of the interviews we prepared a conversation guide. All participants were asked to talk about how asbestos had affected their lives, either directly at work or indirectly through family or community relationships. Workers and their families were specifically asked to talk about their jobs, living with asbestos disease, caring for a sick family member, their experience of the medical and legal system, as well as wider asbestos issues in the Latrobe Valley and what should be done about them. Community members were asked to discuss the social and political effects of asbestos, what they thought the issues were and what should be done about them. While the conversation guide served as a reference, the interviews were allowed to follow their own course at the interviewer's discretion, providing opportunities for unanticipated themes to emerge.

Interviews were conducted over the four-month period, May–August 2003. All interviews were audio taped, and observations were noted by the interviewer as soon as possible after the interview was completed. Transcripts were made of the interviews, which were then checked and edited by the interviewer. To protect confidentiality, pseudonyms have been used throughout the report when quoting from interview transcripts.

Participant observation has also been a vital part of the research process, and has involved our attendance at community meetings as well as informal discussions with members of community and asbestos support groups. In addition, the incorporation of historical and contemporary secondary sources was seen as an important component of data collection. This involved an ongoing review of media reports (newspaper, radio and television) and historical material related to the power industry.

3.3 Analysis

The first analysis step involved reviewing the transcripts and editing where appropriate to achieve maximum accuracy and clarity. This also allowed a preliminary assessment of the data before coding began. Coding involved going through each interview transcript and labelling concepts, ideas and themes related to the research questions. Analysis focused on *how* people talked about issues as well as *what* they said, examining the implicit and explicit evaluations embedded in their narratives. The coding process fragmented the interview narratives into various categories of themes or concepts. Each labelled quote was examined in detail to see what it added to an overall understanding of each theme. As new themes and categories were added to the analysis, all transcripts were recoded iteratively until the analysis process was complete. The data was managed using a qualitative analysis software program called 'Nvivo'.

In the next section, our findings are presented by theme. Based on current understanding of the social impacts of occupational disease [26], our previous contacts with people in the Latrobe Valley, a review of the relevant historical and other literature, and our on-going review of media coverage, we anticipated that several broad themes would be examined in the analysis of the transcripts. These included: development of the workers' knowledge of asbestos; living with risk from past exposure; experience with medical professionals; compensation processes; lack of healthcare facilities; and recognition from the State government. We also found that additional themes emerged from the narratives. These were: women's involvement in advocacy and support; an increasing death rate in the Latrobe Valley; the wider social and political situation in the Valley; the need for increased awareness and education about asbestos; safe disposal of asbestos in the community; prevention of further exposure (both workplace and domestic); and the importance of locally grounded research.

3.4 Interview Participant and Community Feedback Process

A draft of this report was first presented in print to interview participants, who were invited to provide feedback in writing or by telephone. Participants' comments were then integrated into the report and a revised draft re-presented a month later, both in print and in oral presentation/discussion format, to the general community at an open meeting advertised in local newspaper. One purpose of doing this was so that the direct participants and the represented community could continue to contribute to the research process. The community meeting was tape recorded, with the verbal consent of the ~thirty attendees, transcribed and added to the narrative database of the project. Roughly three-quarters of the meeting attendees (~twenty-three of thirty) had not been interviewed in previous stages of the study. Thus, in addition to previous interviewees commenting, questioning and reflecting further on their experiences and on our findings, we also gained some new individual perspectives.

The interview participant feedback and the community meeting also served a validation function. There are numerous views on the need for and methods of validating qualitative research findings (20). The approach we used articulates well with participatory action research—presenting findings to individuals or groups that belong to the group represented by the sample, requesting their assessments of: the degree to which the findings 'ring true', what's missing, what's wrong, and so on (20). Findings in this regard are presented in a separate section below.

4

Findings

In this section on findings, we first present an overview of how the community came to know about asbestos and its hazards, as some understanding of the history is crucial for understanding the current situation. When speaking historically, workers place asbestos in the context of their working lives. When speaking about the current situation, workers, their families and community members place asbestos in the context of their daily and personal lives. Next, we present a distillation of community views of the most important asbestos disease and associated family, community and other issues in the Latrobe Valley. Finally, we look at how interview participants think these issues could or should be managed.

4.1 Development of Knowledge

Workers' knowledge of asbestos

It was widely understood by the workers we interviewed that access to information about asbestos risks was difficult, and in most cases wasn't even an option.

Yet workers recall the visible evidence, from their first days of working in the power stations, that they could see there was a lot of asbestos dust around. During their daily work they would be cutting through asbestos to make repairs, or dust would be released into the air from the insulation around the turbines and boilers. Some workers, like Brian, talk of 'clouds' of dust obscuring their vision, of wiping the film off their coffee cups and throwing 'snowballs' of asbestos at each other.

We used to work on the turbines which were covered in white asbestos lagging. We used to climb over that, it was just like fluff and it used to blow up into the air and we used to throw it at each other and play in it and have a good old time. That was just normal.

But when asked what they knew of the risks the most frequent answers were: *'we weren't told anything'*, *'we didn't know'*, and *'there were never big notices, "keep away, there's asbestos about"'*. One indicator of employer awareness of the hazard would be the supplying of personal protective equipment, but even that wasn't on offer until well into the 1980s. Ray remembers: *'I can't recall any warnings at all in 1980, and I think you might have had masks, but that was for coal dust, there was nothing said about*

asbestos. And Beth, speaking about her husband's experience, says: *'there was no warning, no protection, masks or anything. You would sometimes put a hanky over your mouth.'*

The idea of risk and any feelings of danger were not discussed; they remained below the surface and were not often spoken about. More obvious dangers were apparent in the power stations and workers were concerned about risks *'you could see, not what you couldn't see'*. Although there was a certain level of awareness, the risks of exposure to asbestos were talked down by their employers. As described by Brian: *'It wouldn't have been said "Oh wear a respirator because you are working in asbestos", or anything like that. Those sorts of things weren't heard of.'* Looking back they wonder why they were never told anything; some admit that, to a certain degree, they were vaguely aware of some sort of danger but were grateful to have secure employment.

Betrayal

Workers spoke about a growing awareness and discomfort with the dust in their work environments. They remember back to a dusty workplace and how, in hindsight, this was a signal to them that it may have been bad for their health. Asbestos was, therefore, clearly visible in the workplace environment in one sense; however, workers' knowledge of the hazards of exposure was very restricted. As David describes: *'there was no awareness... most people knew it was bad, or could be bad, but that was as far as it went'*. Most now realise that their employers must have been aware of the dangers, and that they did not pass on to their employees the information available at the time. Although some began to question their managers in the 1970s, and may have been worried about the health risks, workers were more concerned about keeping their jobs. Industrial action did not seem to be an option until much later on, although strikes over working conditions such as wage rates were quite common.

Workers described feeling exploited, betrayed and cheated by an employer who they believe put them all at unnecessary risk for the sake of higher productivity. There was a strong feeling that *'it was pushed under the mat'* and ignored by the management of the SEC. All of the workers we spoke to believe that their employer knew of the dangers, but was not upfront about communicating this risk to their employees. As Michael says:

Oh, they knew, they knew about it, all right, but they didn't want to tell the boys. It's as simple as that. They knew all about it. They knew in 1935 about asbestos. But they said, 'Oh well, you've got a job. Just put up with what you've got'... but that's the way it was.

James, who was in a supervisory position at the SEC, spoke of the dilemma he faced when he confronted his employer about the possible risks and was told to keep quiet about it.

When we approached management, they said, oh, there's not a problem with asbestos and later on the cry got louder and louder and me being a supervisor, they were saying to me, 'Look, the men on the shop floor—don't talk about it, talk it down. It's not a problem.' And that's what I had to do to my men. The SEC knew that it was a big, big problem, but they weren't telling anybody.

Knowledge and awareness: Non-interview sources

In summary, interview participants have indicated that information about asbestos was either unobtainable or suppressed, and that queries to management were 'talked down'. These views are supported by several other sources, such as investigative journalistic reports aired on the *ABC Four Corners* program ('Power without Glory' documentary, 26 February 2001), and a Melbourne *Sunday Herald Sun* (3 June 2001) interview with former Yallourn GP, Dr Geoffrey Danger. Dr Danger reported that he had discovered asbestos disease among SEC workers in the mid-1960s, but when he raised concerns with SEC management 'no one listened'. He says he 'had to go on writing [sickness] certificate after certificate because they sent them back—they would not accept it'. As the article states: 'his reports that asbestos had contributed to the deaths of workers were rejected and he eventually left the Latrobe Valley in 1970'.

Knowledge of the detrimental effects on health of asbestos exposures has been documented in the medical literature from the early 1900s, starting first with asbestosis, then later with asbestos-related mesothelioma and lung cancer (for a summary of the development of this knowledge, see [27]). While these reports were sprinkled throughout the medical literature, higher profile government studies had also been conducted in the UK and elsewhere, for example, the 1930 Merewether and Price report [28]. Although it might have been the case that SEC management was not aware of this growing literature, occupational health and medicine professionals advising the SEC were—and they provided repeated warnings to the SEC starting in the 1940s. In 1944, internal SEC documents record that Dr Douglas Shiels, head of the Industrial Hygiene Division (IHD) of the Victorian Department of Health, noted the presence of asbestos following his tour of Yallourn Power Station. He warned that asbestos was 'one of the most harmful dusts' to humans as it 'causes fibrosis of the lungs' [29]. Ten years later, a note written by an SEC Officer to the Assistant Manager of the Personnel Department records a meeting with Drs Shiels and Thomas from the IHD. Dr Thomas is recorded as asking what the SEC was going to do about the 'known cases of asbestosis and other dangerous concentrations of dust within the organization'. This was followed by a considerable amount of discussion 'regarding the hazards of asbestosis [*sic*] and statements that the Commission had not taken the necessary precautionary measures'. The author of this note professed ignorance on these matters to the IHD officers and concluded it with a request for guidance on the matter from his superior [30]. In 1965, a former SEC worker describes a footnote

in an IHD inspection report—prompted by union concern about another hazard, leaking combustion gases—noting the IHD officers’ concern at the high levels of asbestos fibre in the station air [31].

In summary, information was available to the SEC, over several decades, on the hazards of asbestos and the need to address them, including warnings about conditions in Commission workplaces from medical officers of the IHD. This produced virtually no response from the SEC, with little or no hazard information given to workers and little or no action taken on asbestos dust control until 1980, when employers were forced by the unions to address the issue [31, 32]. A similar story of asbestos hazard information either being suppressed or made difficult to obtain has been played out in various contexts around the world. These cases have been well documented, for example, in literature on the United Kingdom, the United States, South Africa, and elsewhere [2, 6, 33–37].

Wendy, in describing the situation at the SEC in the Latrobe Valley, sums up the story as it was for many communities around the world:

The knowledge was locked away. The asbestos industry and its insurers knew, some doctors and scientists knew, some governments knew, but workers and the community didn’t know.

4.2 Community Views: The Issues

Throughout the 1970s and 1980s, asbestos exposure continued in the power stations in the Latrobe Valley. In 1979, the unions initiated a ‘taskforce’ to deal with the dangers associated with asbestos exposure for workers, and increased pressure on the management of the SEC to do something about it. But daily exposure was still occurring. The risk associated with this was not clearly understood or communicated to workers and often suppressed altogether. Family and community members became involved as awareness grew about the risks of exposure both inside and outside the workplace. Wendy, for example, became directly involved in union campaigns, supporting her father, while others found they were helping friends or neighbours with sick relatives. The increasing numbers of people becoming ill from exposure to asbestos was one of the first signs of the seriousness of the problem in the Latrobe Valley.

It was in this context that the dangers of asbestos became apparent to the wider community, firstly, through the actions of the unions and, secondly, as illness from asbestos disease spread throughout the Latrobe Valley. This section details how, in the interviews, people spoke about these issues as being part of their everyday lives in regard to asbestos disease.

Anger

Given that workers had little choice in working with asbestos and knew very little of the long-term outcomes, most now view the fact that they have to live with the effects of exposure to asbestos with a mixture of emotions. People expressed feelings of anger, particularly those suffering from asbestos diseases. They felt that management knew more than they were telling people, but they were not using the information they had to control the known risks. Noel suffers from pleural plaques and describes the price he has had to pay:

No doubts that it was very beneficial to the area, but it's a pretty dear price you're paying for a few comforts, isn't it, when people are paying with their lives...it's a pretty dear price to pay for progress, isn't it? But it's a cruel thing, because you know, it had been known for so long that it was detrimental to people, their health, you know. I'm more crooked on that...than sort of having it, you know, because we should have never been exposed to it like we were.

Living with risk from past exposure

Among most workers with an asbestos exposure history who have not developed asbestos disease, we observed a conscious preference not to talk about the risks. They consciously choose not to think about it, to put it to the back of their minds until it actually affects them directly. The following is an excerpt from a group interview with five ex-SEC workers who were exposed to asbestos but have not as yet been affected by asbestos disease:

- Ray:* I don't want to know if I've got asbestos.
- Tony:* Yeah. I think it's nearly pointless. If you get it it's a death sentence, you know.
- Ray:* Mm. Worse than AIDS.
- Tom:* Well, exactly, I agree. If I got it I don't want to know it because...
- Tony:* It's scary stuff.
- Tom:* If I've got a bit of quality time, and I don't know about it, I'll use it but...
- Ray:* It's insidious.
- Tom:* Yeah, exactly, yeah, it is.

As well as a sense of uncertainty, other reasons given for not wanting to know if they are affected include fear and the fact that they see no evidence of a cure. On the surface, this could be viewed as a form of denial or fatalism. It is better

understood, however, as a rational decision based on the (medically accurate) knowledge that neither early detection nor treatment for any of the three main asbestos diseases confers much health benefit to the affected person. As Larry describes, people feel nothing can be done:

They don't really want to be bothered too much about trying to find out whether they have been exposed or not. I think there is this real sense that if you've been exposed and if you are going to die from asbestos-related disease... a lot of people say 'what do I need to know for'. There is nothing that can be done, there are no resources around here for me anyway, the longer I know the more I'm going to worry about it and I might as well have as many years living in ignorant bliss as I can before I get diagnosed and get told that I've got eighteen months to two years to live.

Further, because it is such an emotional issue people may choose to avoid the issue directly, which Trish says is understandable:

Dealing with it isn't easy when you know that you've been exposed through [the] negligence of somebody else. And then I guess it's the unpredictability of how it affects people and people can get different stages [of disease]. I think it's sort of like a lack of understanding of where you... where you can end up.

She also mentions the fact that as asbestos is such a 'political' issue, it may be seen by some as a reason not to think about or take action on it:

I just think because it's been such a political issue and a hot issue and so many people have been exposed to it, there's a lot of male population that don't want to know anything about it, they don't want to know if they get sick, because that's the way they deal with it. They've seen what it can do and heard everything so [they think] if I don't go to the doctors and find out if I've got it, then I don't have to deal with it.

Although some may not want to know if they have asbestos disease, those who are still currently employed in the power industry are adamant about the importance of health and safety issues at work, and all agreed that they will not work in areas known to contain asbestos. They feel secure in the fact that their unions will support them in this decision.

Another aspect of living with risk from past asbestos exposure is the multiplicative interaction between cigarette smoking and asbestos with respect to lung cancer risk. Participants were aware of interactions between smoking and asbestos exposure, especially those with asbestos-related conditions who had seen specialists. As related by James, a former SEC worker with pleural plaques:

One of the specialists that I spoke to about asbestos said whatever you do, avoid passive smoking as well, and if I was to take up smoking now it would kill me, there is no doubt about it. I have x-rays here of my lungs and you can see it's full of asbestos.

While many interviewees were critical of those who smoked—especially those who were also asbestos-exposed—some expressed suspicion or resentment for the focus on the role of smoking among asbestos-exposed workers, viewing it as a continuation of the historical denial of the asbestos-relatedness of what are now clearly established as asbestos-related diseases. As recounted by Nancy, the widow of a man who died of an asbestos-related cancer:

He was a non-smoker, but you know they try and put it on to that but I really don't believe it. I'm not saying it does you a lot of good, because I never smoked. But they blame everything don't they? They keep at it... did you smoke? Did you smoke? You know.

And Diane, a widow of a lung cancer victim, explains her understanding of her husband's illness:

They just reckoned it was smoking that caused lung cancer, but of course the smoking and asbestos made it worse.

Notably, of the nine asbestos-exposed workers in our study who were former smokers, only one had quit because of asbestos concerns (this includes seven workers interviewed, plus two we learned about through their widows). Similar findings have been made in larger surveys. For example, in a survey of 214 US asbestos workers only 3.4 per cent of ex-smokers quit due to knowledge of smoking–asbestos hazards [38]. Larry, a former SEC worker, in response to being asked why he gave up smoking years ago responded:

Oh, just heart disease and that smoking was not good for your health. Like I've given up sugar, I've given up smoking...

Others quit more out of concern for others than for themselves, as illustrated by Brian, a current power industry worker:

Brian: I was well into my career before I started with kids so at that stage I gave up smoking which has probably held me in good stead too.

Interviewer: Did you know about asbestos and smoking?

Brian: No, it was more about smoking around the kids. No, it wasn't because of asbestos.

The observed preference of asbestos-exposed workers not to talk about associated disease risks (smokers and non-smokers alike) may understandably, though ironically, flow on to a decreased concern about the health risks of smoking. This possibility should clearly be explored further to inform smoking cessation programs for this population group, which have shown generally disappointing results [38–40]. These observations, coupled with the fact that few smokers who quit are motivated to do so by their asbestos exposure, indicates the need for new strategies. Further community-based qualitative research could yield novel strategies as well as insights for optimising traditional approaches—e.g., media campaigns, physician advice. In summary, these perspectives on living with risk from past asbestos exposure provide valuable information for the design of medical screening, smoking cessation and other early intervention programs.

Experience with medical professionals

Although some workers felt they didn't want to know their health status, those who actually have asbestos-related diseases are more active at seeking out health information. This is often due in large part to help from their partners or family members who may initiate such a search. Although the desire to become informed is quite strong, workers still feel as though access to information is limited. James describes his experience with a lung specialist as very vague in relation to detection and diagnosis of asbestos diseases.

Like I said the specialists won't tell you anything. You'll ask them questions and they'll give you the same answer all the time, but they really don't know, they don't know. They don't seem to be pushing to find out better ways of testing you. I can't understand why it attacks some people so vigorously... it seems to be if you have it, [there's] absolutely nothing that they can do.

There was also a large degree of uncertainty around when the symptoms of the disease would appear due to the long latency period of some diseases. This led James to describe it as 'living with a time bomb on your chest'.

They have said to me, 'Look, we just don't know. You might go all through and die of a heart attack or old age or anything or tomorrow it might decide to inflame and if it does, well, that's it.' And there's blokes that worked for me whose funerals I've been to...well, the last bloke I went to, he was more than ten years younger than me and he worked under me on the same job. He was my leading hand, and he's dead. I'm still kicking around, and the medical profession, either they don't want to tell you or they can't tell you why.

James also made an interesting point about the medical profession's differing reaction to a disease like diabetes. A few years ago he had a health scare and had to

go through a series of tests for diabetes. He was stunned by the contrast of this experience with that of asbestos disease. With diabetes there was a wealth of information he was able to access and people were actually sending him information all the time. He was also put on the diabetes register so they were able to monitor him and check for any changes in his condition. With this aspect of his health he feels in control—he is able to access knowledge and he feels that people care about his condition and wellbeing. He also seems to feel more reassured by the fact that he can take blood readings and see changes depending on how much alcohol he has been drinking or what food he eats. His health feels more under his control. Thus, on top of other asbestos disease concerns, the lack of a sense of control appears to deepen the emotional impact.

Initial diagnosis is something many people felt shocked by, followed by uncertainty surrounding the progression of the disease to something worse. As Louise, an asbestos support group member, describes:

People don't expect to get a diagnosis like that. They've often even forgotten about their exposure so they've got to deal with their diagnosis, they've got to deal with their health treatment things, they've got to deal with, you know, the prospect of maybe I'm going to die and it might be soon. It's a very emotional issue and a lot of these people actually need counselling to help them deal with it, they've have seen their workmates die and it's a case of sitting and thinking when is it my turn?

Healthcare facilities

As mentioned previously, there are a large number of people suffering from asbestos-related diseases in the Latrobe Valley, and this number is on the increase. When speaking to people, particularly those suffering from asbestos-related disease or family members caring for relatives, they all mentioned the inadequacy of health care facilities in their local area. When we asked people to speak about their experiences, many spoke of the time spent travelling to Melbourne for treatment. Donna describes the experience with her father:

My dad had to stay down there [Melbourne] for a week when he got it. I mean my dad had to get the train. He had no transport unless we took the day off work or something... we did it when we had to.

Simon, a union organiser, provides another perspective:

If you've got cancer or you've got mesothelioma or asbestosis, you really don't care whether somebody studied it to death and you are on a register and you've got a letter of exposure. If you've got to get in the car and if you are dying and you've got to drive all the way to Melbourne to get treatment, it's not fair in our view.

As a result of feeling isolated from adequate health care facilities, people spoke about caring for relatives at home. All of the six women we interviewed who had lost husbands or fathers through asbestos-related diseases had cared for them at home during some stage of their illness. Their stories were ones of extreme strength and determination as they spoke of those difficult times:

Mum and I looked after dad at home; he never went to a respite, hospice care facility. She and I took it in turns to look after him, twenty-four hours a day. And dad wanted it like that. So that it was still a caring environment and a homely environment and I think that's why a lot of people choose to stay in their homes, even though their families are just run ragged looking after them. I know my mother was. She was exhausted. By the time my father died, I reckon it would have taken her at least eight months to get over my dad's death in her own, health wise. It was pulling her down, let alone me.

Some of the difficulties these women expressed included not knowing how much pain the person was in combined with the feeling of not being able to do enough. Often it was the person's wish to be at home during their illness but most ended up in hospital in the final stages. This was very difficult for the family as they struggled to regain 'normality' in their lives after such an intense period of dedication to care giving. Louise describes the pressure families are under during these times:

It puts a burden, a real burden on to the whole family. [With an asbestos-related illness] you're just struggling to breathe, you can't do anything. They get very dependent, their wives become a carer and then that affects the wife's life, you know. She's happy to look after him but it then means that she's got no life for herself; she's got no time left. So there's large amounts of active community care that are needed to help and sustain that family while they're looking after somebody who has been affected.

Increasing death rate

Most participants spoke in one way or another about the numbers of people who are affected by asbestos-related diseases. Some told of the people they know on their street who are ill, or the people they used to work with who are now sick or have died. Some talked in terms of estimates of the total SEC workforce and how many of these would have been exposed in their daily work. Strikingly, each participant spoke about people they knew who had died from asbestos-related disease. These were friends, neighbours, or work mates. Current workers like Brian feel lucky to be in good health, especially because they worked in the same areas of the power stations as many affected by asbestos-related disease:

It is a case where twenty to thirty years have gone by where we've had major exposure to it and people of my generation are going down. I've

talked about [three other workmates] and it quite easily could have been myself and then I think about all the other people that I know that have sort of gone. If I think about it, there are probably twenty or thirty of them in the last ten to fifteen years. So it is a serious situation.

Some, like Trish, understand the number of cases to be still increasing due to the long latency period of the diseases. They see clear evidence of this when they look around their neighbourhoods.

I know it's a huge, huge problem here, and it's not going to get any better. Well, I mean, the exposure to asbestos won't really happen until about...won't peak until about 2020, so you've still got a lot of issues to deal with.

Simon is angry that *'the asbestos issue in the Latrobe Valley has just been paid lip service'*. Instead of trying to quantify the numbers of people affected, he believes more consideration should be given to the provision of adequate services:

It's pretty hard to put down the actual data, but when a lot of people keep saying the same thing to you, you've got to say, well, there's got to be some truth in all those issues. People can do as many studies or write as many papers as they like. I think the real issues are that they need to have those [healthcare] services here for people in this area.

They also worry what sort of impact this has for their sense of community when so many people are affected. It makes the need for a broader community response even more of a priority for the people of the Latrobe Valley.

Quality of life

Lives and lifestyles are changed in permanent and significant ways as a result of asbestos-related illnesses. Nearly all of the people suffering from asbestos-related diseases and their families felt strongly that they had experienced a diminution in their quality of life. Some were finding it difficult to come to terms with a loss of independence, or were concerned about becoming dependent on others for their daily needs. They described not being able to do basic things around the home, go shopping, visit relatives or travel. Several people spoke about the plans they had to travel around Australia, or other things they wanted to do in their retirement years that they were now unable to achieve. Noel describes the effect on his life:

What asbestos means to me is that it actually ruined my life... You sort of lose your self-esteem I think when you've got to rely on other people, to ask other people to do so much for you, it's sort of... I don't know, degrading I think... particularly when you can't do your own shopping and

things like that, it makes life pretty miserable, but then you've got to make the best of what you've got I suppose.

Living with asbestos disease also affects identity. The transition from being a healthy and independent person to being physically limited and reliant on family and others leads to feelings of anger, frustration, fear and uncertainty. Louise speaks about the many dimensions of an individual's health, illness and identity that are deserving of attention:

It's holistic care, so you look after the illness and then the rest of the things, because the person has all these other aspects, it's not just the medical issues, it's the other social issues, quality of life issues, emotional things and their care that have to be looked at as well and to provide good care for somebody, you have to look outside just the illness.

Compensation process

People had many comments about compensation issues, be it in the form of workers compensation or a civil suit. Some have received letters from the power station management detailing their exposure to asbestos, which they see as a blessing in disguise. For although workers feel that these letters are an acknowledgment of liability, as Tom says *'it doesn't make you feel very good, it is something you would rather not dwell on'*. And most people we spoke to felt the compensation process to be overly lengthy and complicated, requiring them to prove that they were exposed to asbestos. As Larry suggests:

At the end of the day if you have mesothelioma and you have had a reasonable exposure to the power industry that should be enough, simple. For someone who is an industrial worker in the SEC that should be enough, no more arguing about it.

If payments are made they often arrive near the end of a person's life, which has led some people to choose not to fight for compensation. As Noel says: *'I'm not worried too much about compensation, I'd rather have years than money. I just haven't got the energy to worry about it; I just worry about day to day.'* Other people like Miriam, a widow of an asbestos-disease victim, would like to have some security that families will be provided for in the event of a worker's early death: *'I always wanted to have something to leave to my kids because it was their dad they lost too early'*. This feeling is shared by Tom who believes a letter documenting his exposure to asbestos will ensure that his wife is compensated in the event of his death from an asbestos-related disease:

I got a letter that says that I'm exposed to asbestos and if I'm going to die of asbestos I know that my wife is going to be looked after... I know if I've got it I'm more or less history, but I know that my wife won't have to fight to get compensation, that this is going to stand up in court that they

admitted to guilt, which they have, and that's what that letter says, that I have been exposed to asbestos.

They also worry that their families may be at risk through take-home asbestos exposure, and would like some guarantee that family members who become ill will be looked after.

Stewart is aware that the legal ramifications of admitting to a relationship between work-related illnesses and asbestos deter employers from openly addressing it as a problem:

I know the problem you'd have is if you're talking about it in forms of compensation, you're talking about a massive amount of money... But no amount of money compensates you anyway, does it?

However, a recent case mentioned by Brian has been taken by some as a sign that things may be changing in respect to the compensation process:

[His death] sort of set a benchmark for future claims, in as much as the SEC acknowledged they were responsible for it... it means that it is the first time that they've ever said, 'yeah we have a case to bear, we actually had our workforce exposed to asbestos and we didn't do enough about it'.

Even though claiming compensation is becoming more straightforward, people feel that the amount of money they may be awarded is not as important as an apology or acknowledgment of past wrongs.

Women's involvement

Family members of people with asbestos-related diseases are involved in support and advocacy issues in many ways. They often provide medical care, as well as running the household, working full-time, doing volunteer work and providing emotional support. As a way of coping with this increased pressure several of them have sought support outside of the family. For some this happened after the death of their husband or father as they struggled to understand and work through the grief process. Leonard, the current president of GARDS, or the Gippsland Asbestos Related Disease Support, describes the process behind the establishment of the group in 1993:

I found out that a lot of the people I had worked with had been affected with a new disease called asbestosis. And at that time I met a lady called A.B. She had just lost her father because of an asbestos-related disease and [we wondered] 'why isn't there a support group to help these people and these families that have been afflicted with asbestos-related diseases?' And she said 'I know a lot of ladies who are widows who are walking around

the streets of Newborough who have lost their husbands and I believe that it is the result of asbestos-related diseases'. We didn't know but we suspected and our suspicions were true. So as a result of that we called a public meeting and we formed what is now called GARDS.

A.B. said to me, 'these ladies don't know what action they can take, what they can do, isn't there an area where we can bring all these ladies together'. They didn't know whether they were entitled to compensation and they just wanted support, they just wanted people to talk to. They were lonely, they wanted people who had like interests to them so they could get together and have an experience to meet people and rather than just sitting at home, they had someone to talk to.

As a further development from the initial seeking of support, some women have gone on to make their asbestos concerns more public, both in the Latrobe Valley community and beyond. GARDS, for example, started as a support group for widows of former power industry workers, later expanding its activities to take on an advocacy role as well. Leonard describes part of the group's role:

The night meeting which we are having tonight is more of an advocacy meeting that we agitate to get asbestos problems solved. We talk to members of parliament, we write letters of complaint if asbestos is not being used properly. We are probably a semi-political group.

With support from local trade unions, lawyers and health care professionals, GARDS recently sent a petition to the State government requesting that the issue of inadequate health care facilities in the Valley be urgently addressed. The petition received support from people around Victoria, and attracted a total of 7400 signatures. The government has since announced that a Cancer Treatment Centre will be built at the Latrobe Regional Hospital at the end of 2004.

Families have also become involved in making the local community more aware through donations of money for oxygen concentrators, sponsoring asbestos information booklets, and distributing GARDS newsletters and pens to local businesses and community groups. A number of people mentioned that although they support what GARDS is doing in regard to asbestos concerns, they didn't feel that they could be personally involved. For some it was too painful, 'heart wrenching' or depressing to attend the meetings while others didn't feel well enough to leave the house. Nevertheless, these people and many others in the Latrobe Valley donate their time, resources and money to support this group in their activities. Donors even include current power industry companies. The growing activities and networks of GARDS illustrate how asbestos issues in the Latrobe Valley reach far wider than just those who have been directly exposed. The people of the Latrobe Valley have mobilised and developed their own community capacity to meet the support, communication, advocacy and other needs of those affected by asbestos-related diseases.

Wider social and political situation in the Latrobe Valley

The SEC was privatised in 1994 during an era of economic rationalisation and privatisation of public enterprises under the Kennett Liberal government (also described briefly in Section 2 above). Since the SEC privatisation, and a series of cutbacks in health, education and government services introduced during this era, many jobs have been lost in the Latrobe Valley [41]. For example, a power industry workforce of 8481 in 1990 has been reduced to a current level of around 3000, which has had a significant impact on the local community, both economically and socially [42].

Speaking about the current situation in the Latrobe Valley, Larry (a union leader) expresses some ideas on why people may be feeling a sense of urgency and desperation in regard to the social and health needs of their community:

Well socially I think regrettably the whole restructuring and privatisation in the electricity industry was done on the basis that it was supposed to provide better services to the consumers via competition. Regrettably the Latrobe Valley community wasn't considered in any of that, there were no discussions or any sort of resources put into the hurt that would be caused as a result of this restructure. The Latrobe Valley community essentially was left with the brunt of the change. And while the change was going on it was so dramatic that the Latrobe Valley workforce and community were never able to get together to coordinate any proper response to the devastation that was occurring around here.

When asked what he had noticed, he listed the following: *'High unemployment, high suicide rates, lots of business closures, lots of people over forty out of work, very depressed economy, low real estate values all that sort of thing, that's what I've noticed'*.

He suggests there may also be a lack of cohesiveness that is making it difficult to work together as a community to initiate positive change:

There is no coordinated voice and there are a lot of little groups in this community trying to do things about their own little patch, like the GARDS group or the trade union movement about the workforce or the small business community about business, but there is no coordinated response to the problems.

He goes on to explain how local government is trying to address this:

I'd say also in the Latrobe Valley there is probably not a community person that is recognised as a Latrobe Valley community citizen. There needs to be a group of those people established, that have got the real Valley interests at heart. I think there are enough people in the Latrobe Shire that recognise this lack of central or community spirit and they are trying to overcome that by locating the community centre, the Latrobe Valley Shire

offices in Morwell and they are hoping that will be a catalyst for a united Latrobe Valley.

However, there is evidence that at least one group of people who got together primarily to support each other has increasingly become part of a wider social and political network that is dealing with asbestos issues on many levels. A good example of this occurred at the May 2004 wreath laying ceremony and memorial quilt display in Morwell Rose Garden (*Latrobe Valley Express*, 6 May 2004, front page) organised by GARDS, at which friends, families, union members, local lawyers and other members of the community gathered together to remember those lost to asbestos-related disease. As awareness grows for the work that GARDS does, it is more likely that people in need will be able to use them as a resource. Recent endorsements of GARDS' work have come from both the Gippsland Trades and Labour Council (GTLC) and the Latrobe City Council. The GTLC voted unanimously to support GARDS in its endeavours and the Latrobe City Council has shown financial and other resource support.

4.3 Community Views: What Could or Should Be Done?

In this section we present an analysis of the views of interview participants on ways forward in addressing asbestos issues.

Acknowledgment/recognition from State government

Workers feel betrayed by the State Electricity Commission and would like to see some acknowledgment of the problems surrounding asbestos and a move to redressing these. As Simon and Larry (both union leaders) suggest, the current State government should be taking more responsibility for the legacy left by the former SEC.

We are talking about the old SEC which was government owned, where this epidemic of asbestos is coming from. We believe the government has still got some responsibility there and even besides that, we also believe that the government has got a responsibility to try and meet the health needs of the community, irregardless of whether it's because they were party to the SEC. I mean, even if it had been private corporations that owned it back in those days and people were exposed to asbestos, we still believe that the government has a duty of care to try and meet the health needs of people, especially people who are dying of these terminal diseases. (Simon)

Well I think one thing that government definitely needs to start doing if it wants to supposedly help the Latrobe Valley people, it should talk to Latrobe Valley people... [but] they don't want to hear real things. They

don't want to have real solutions, they don't really want to do anything long term and decent. (Larry)

There has been no move by the SEC or by successive State governments to acknowledge publicly the significant loss of life in the Latrobe Valley due to asbestos exposure in the workplace. There has also been no mention of the years and years that people were denied access to knowledge that was clearly available. Workers, their families and the wider community would like some form of apology or recognition as a step towards individual and community healing. Ben, the son of an asbestosis sufferer, describes his reaction to the Wreath Laying Ceremony and the need for community grieving to be addressed at a wider level:

There is a lot of emptiness which reminds me of the grief process. Not so much for the victim but that [community] process which needs addressing. So when people talk about their grief it needs a deeper understanding of what they are saying... the mental health perspective needs more research.

There have been no attempts made by any State government in the years following privatisation of the SEC to acknowledge or to apologise for those actions taken when the SEC was a public corporation. Leonard from GARDS has some concrete suggestions for a possible way forward:

I would like people in authority, to recognise that there is a problem. I would like some financial help because everything we do here is all voluntary, we get no assistance from the government. No assistance from anyone, any big industries. A little bit of support, a little bit of help, a little bit of recognition of what we are doing and then it would make things a lot easier for us. People are denying that this is happening and if we can get over that hurdle I think that would solve a lot of our problems.

Simon agrees that there has been a historical culture of denial around asbestos hazards and asbestos-related diseases:

At the end of the day, people are going to have to face up to it that people were exposed to asbestos and people will die of asbestos-related diseases. Governments that dealt in it, they know what the issues are and they are [saying], 'well if we don't mention it they might just all die and go away'. Well it's not going to happen. They're actually using the tobacco industry tactics in dealing with asbestos issues.

James, an ex-SEC worker, expresses his accumulated anger and frustration with this historical culture of denial, graphically illustrating how the past continues to affect people's feelings in the present and the need for reconciliation on these issues:

Well, I want them to recognise that fact, too. Tell us. Admit that they do know all about it, that they did know about it when they were still putting it in bloody power stations, and come clean instead of running around and trying to look at you as, ughh, you know, you'll die one day and we won't have to worry about you.

Healthcare facilities

The lack of adequate healthcare facilities for people with asbestos-related diseases is a problem that many feel needs to be addressed urgently. Although people are partly coming to terms with the legacy of asbestos—through local community organising and speaking out about their concerns—the lack of adequate health care facilities to deal with the current numbers of people suffering is something they feel should be addressed immediately. Larry suggests some options:

We think there should be a resource in the Latrobe Valley available to people to be able to x-ray them, rehabilitate them, provide palliative care and all of that sort of thing, here in the Valley. People who are diagnosed with Mesothelioma who have got six months to live don't want to be spending a lot of their time driving up and down the road to Melbourne and sitting in waiting rooms trying to prolong their life for six months when they have been hit with the lucky stick of asbestos, asbestosis.

Services they feel are needed include: provision of oxygen concentrators, a radiotherapy treatment centre, a specialist hospice, palliative care facilities, specialist respiratory medicine services, a professional counselling service and GP education on asbestos-related diseases.

As mentioned previously, the State government has promised funds to build a Cancer Treatment Centre in the Latrobe Valley. While some commitment has been made it is not really clear to the community what the Cancer Centre will include:

It is going to help people with asbestos injury and it is going to help the diagnostic problem that has been down there for a long time. But it does not address the lack of palliative care facilities, the fact that there is no professional counselling service, that people still have to be transported around the place, this whole range of issues that still need to be dealt with.
(Wendy)

Louise explains how even the provision of supplemental oxygen would greatly benefit those with asbestos-related disease.

Most people with asbestosis will eventually get to the stage of needing oxygen and supplemental oxygen and that's... availability of that is another major issue, when people are really struggling to breathe it really hampers their life and what they can do if they have difficulty breathing.

Supplemental oxygen just improves their quality of life. It's not a treatment to fix anything. It [simply] improves quality of life.

Her comment highlights the need to provide services and facilities for chronically ill people with any form of asbestos-related disease, not only those with cancers.

Those in the Valley also compare themselves to other areas of Victoria and wonder why they are still waiting.

Money hasn't been spent to sort of maintain the community like it should be either. Because the people here deserve the same sort of facilities as what Ballarat and Bendigo and Geelong [have]. [They've got] their radiotherapy units. We're still waiting. Our needs are just as great. (Diane)

Once again the importance of working together is suggested by Larry as a way of addressing the issue of poor healthcare facilities.

Policies by the federal government, these policies of individuality and self and competition, don't engender community. They don't engender a spirit of cooperation between people and that is desperately required in the asbestos issue. I think if the Latrobe Valley community got themselves together for twelve months I think we would have an x-ray unit here, we'd have palliative care. You need some sort of a hospice, not a hospital.

Awareness and educational/political campaigns

Most expressed the wish to see an increased awareness around the topic of asbestos, and that the community be educated about the risks of exposure. As an attempt to gain some level of control, and perhaps as a form of healing, people stressed the need for more education about the risks of asbestos exposure to make up for the lack of knowledge in the past. They feel strongly that future generations should not face the same sort of risks from asbestos or any other hazard.

Although it was known to be dangerous, the community wasn't aware. It's really only in the last twenty years and the community is reasonably well aware but there are still people who don't know, particularly young people who say bought a home to renovate, they don't really know much about it. (Louise)

Simon explains the long history behind the use of asbestos and wonders how bad things have to get before something is done:

To say that people or companies or governments didn't know, I mean, it's well documented right back in the twenties and the thirties that asbestos was, you know, a bad thing for people to be exposed to. And I mean, they

used it for the commercial need or they used it for a million years, you know and it's only since we've been filling up graves, that people have been getting mesothelioma and asbestos that it's become an issue.

Diane, a long-term member of GARDS, believes awareness and education to be vital in preventing further exposure:

Awareness I think. That's one of the main things, because people just don't realise how serious it is and it's in everything, you know. People don't realise what it's in. [And] educating people because people just don't believe in it I don't think, and where it is. They just scoff, you know, and they don't take any notice. Awareness, I think that would be the thing, you know getting more advertisements out there. If it's affected you personally you take notice of everything... but if it doesn't they don't tend to listen.

And Helen, current secretary of GARDS, explains how the group is directly involved in educational activities with the wider community, particularly in the area of health care.

We're liaising with the unions at this present stage. They want to be in touch with the community so they're doing that through us, so we're having meetings with them. We're having meetings with doctors in this area now, which we didn't have before. We're keeping them informed of what's going on. Even the doctors want to know what's going on around here, and they do that through us. The general community wants to know and they want to know why this is happening and why it happened so much in the past. The people that were in the places to do something about it earlier on did nothing and they left this wonder product out in the market for people to get sick.

James feels strongly that workers with past exposure should be told that they worked in an asbestos environment, be aware of the health risks, and know what they can do in terms of their own health. He is concerned that there were many workers 'out there' with past exposure who aren't aware of their health risks, and that they should somehow be notified. Others see this as complicated by the possible compensation and liability implications for the government:

Some people think we need to get some sort of asbestos register, like a register of victims or potential victims... There are a whole lot of records around from the SEC days and the trouble is the government doesn't want to do this because I think they don't know what the compensation bill is going to be. They don't want to actually give recognition of the problem. I think they want to maintain disunity. (Larry)

These perspectives should be considered in relation to current and future screening programs for former workers. The notion of informing all exposed workers of

their exposure history, associated health risks, and what can or cannot be done about those risks is supported by best international practice in this area, known as 'high risk notification' [43]. Even where screening tests might not be appropriate, other objectives can be addressed—such as, acknowledgment of past exposure, offers of smoking cessation programs and communication of information on compensation rights. Recent examples and insights can be gleaned from programs set up for former workers in the US nuclear weapons production industry [44], and a long-term follow-up of a notification program for aromatic amine dye workers [43].

As another means to achieving greater awareness it was suggested by a community health worker that funding be made available for GARDS to employ a support or education worker. This would be in support of the work currently undertaken by this group on a volunteer basis, such as directing people to find appropriate information, lobbying on behalf of the community, referring people to relevant bodies and health care providers, and providing counselling.

Larry describes a widespread feeling of concern about asbestos and highlights the benefits of having a group that represents the public's interests.

There is a real concern about the asbestos-related issues right across the Latrobe Valley. I mean every family is affected in one way, shape or another. Every family has got somebody that has been exposed to asbestos. So there is a real concern about it but there is no body that has got the respect of the whole community that is supposedly representing our interests in that area. The problem needs a community response to take in everybody... because there is this real sense of desperation about getting things done about asbestos and there are no proper facilities here to deal with the problem.

Helen from GARDS speaks clearly about what she feels needs to be done:

Well, I'm hoping we can tell the government... we all want the same thing. We want people to be cared for in the Valley and we want this thing to have some sort of end, we want to have the services there that should be there for these people. This wasn't a disease that went through here, this was an industrial epidemic, and they should be putting the services in place for these people. It's not their fault that it happened. You know this isn't just one voice speaking out here now; it's a lot of voices.

Removal and disposal/prevention of further exposure

Concern about asbestos originated with occupational exposure and disease, but has now grown to include domestic and general environmental exposures from any source. Unsafe disposal of asbestos has also become a concern. Louise explains the importance of awareness in regard to its safe removal and disposal:

The main thing is stopping further exposure, alerting the community that this is dangerous, without making people afraid, but alerting them it is dangerous. But the important thing is that they know how to handle it so dust and further risk is not created. So that's the big area that we have to get to, the people that don't know anything about it, and to stop further exposure, because we can't do anything about the exposure that's happened in the past, but it's exposure. And it also comes down to safe removal and disposal. Disposal is a big issue.

Helen showed us an article from the local paper regarding asbestos disposal at the local tip (city council operated). Although the council is offering to dispose of asbestos, people have to give forty-eight hours notice, turn up at 4:30 on Wednesdays only and wrap it themselves in two layers of plastic sheeting. There is also a charge for this service. Louise emphasises the importance of educating people about safety in the removal process.

That's what it's all about, getting rid of it, so educating people how to do it and to do it safely so they're not going to sort of get sick themselves. They're going to do it the cheapest way possible, but they need to realise the cheapest way possible sometimes is not the safest way. So you're far better off to use a tradesman or something like that and get rid of it first and be safe. And that's probably the biggest message that you need to get across. This is one issue where there are big risks and umm, better off to spend a bit of extra money and do it safely.

Larry suggests the State government also has a role to play in ensuring protection of the public's health:

And I think that is something that needs to happen in this area too, the whole asbestos removal and disposal needs to be made so easy for people and affordable that they do it that way instead of doing it themselves. It needs to be properly subsidised at this stage to make sure that people remove asbestos in those ways. The government should really be doing some serious work in those sorts of areas to highlight the problems.

Trish describes how the risk of asbestos exposure has become an issue for the wider community:

You've got a very angry community, and they would like to see things done. The attitude is that they want to make sure that nobody else is exposed, so while they're angry at the past they're trying to make sure that in the future everybody has got the correct information and everything like that so that they don't get exposed, and that people in the valley have got access to treatment. There's a very caring community, they just don't want to see anybody else be exposed and go through anything so that they want to make sure that these changes are in place and that people are educated,

you know, where to find asbestos in your homes and all that sort of stuff and in the workplace, that no one is exposed to it in their workplace.

A request for action on dealing with asbestos that originated in the workplace now encompasses asbestos wherever it is found. Concerns are spread community wide and most people we spoke to wish the risks for future generations to be greatly reduced.

Local involvement in a response

Some people spoke about their wish to see responses to asbestos problems locally grounded, using people conversant with the area and with asbestos issues. Larry suggests that the best understanding of a community and its needs comes from the people who actually live there. He would like to see some local involvement in developing responses to asbestos concerns in the Latrobe Valley:

A small panel of people should be given the wherewithal to begin coordinating the whole asbestos question where the government starts to use a group like that as a resource to determine where they are going to spend their money, what they are going to do. Those people need to have a Latrobe Valley background, they don't need to be currently in the Latrobe Valley but they need to have a Latrobe Valley background, they need to have an understanding of the community and its needs. You can't empathise with a group of people that you don't know anything about so that might be the way to go.

He believes the expertise exists in the community to develop such a response, and gives other reasons why it should come from community members themselves:

There is a real sense too that why aren't the processes run in the Latrobe Valley? Given that this is the epicenter of Victoria for asbestos problems and it is also a region that is desperately in need of employment and jobs, why aren't the initiatives that are run supposedly for this area why aren't they run in this area? We believe that the expertise is here and all that sort of stuff and it should be in this area.

Leonard from GARDS supports this view and stresses the need to listen to the people who know the issues:

If I was talking to the community as a whole, I would be saying to them, we have a problem here, at least listen to the people who know the issues and if we don't do anything about it more people are going to die and at least make some action to try and give the people who have been affected, give them support, financial help.

4.4 Interview Participant and Community Responses to Findings

As described above in Methods, Section 3.4, a draft of this report was given to interview participants whose comments were then integrated. One month later, a revised draft was presented to the general community both in print and in oral presentation and discussion format.

We wished to further explore some themes identified in our analysis of the interview narratives with the represented community. In particular, we wanted to hear more about ‘living with risk’ and ‘women’s involvement’. These were raised specifically in the community meeting, with a request for feedback on our findings as expressed orally and in the draft report. Additional insights gained on these two themes were integrated into the results section above. One point that was made strongly in the meeting, with affirmations from numerous meeting attendees, was the need for the asbestos legacy to be addressed as a community issue—not just a worker issue, a union issue, an issue for families affected by asbestos disease, or a GARDS issue. Further, the view was expressed that appropriate action by government and the healthcare establishment could only be stimulated by various community groups working together and presenting a unified voice. This was well argued by Simon, a local trade unionist:

It has got to be a community issue, what we need to do is broaden the approach to be a community approach. Because I’ve got to say GARDS won’t be able to do it by themselves, the unions won’t be able to do it by themselves, it’s got to be a community initiative and those people in Melbourne when you talk about services for medical things they will not jump up and down until you put the pressure on. One of the things they’re concerned about is their liability, you know—government employer SECV—that’s why the doors are closing, we need to put that out there.

While the main focus was on the future work to be done, meeting attendees also acknowledged the significant progress of various groups working together over the past two to three years. In particular, there has been a strengthening of communication between GARDS and local trade unions, increasing speaking engagement requests for GARDS (e.g., by Rotary and the Masonic Lodge), and growing recognition by the Latrobe City Council of the support and advocacy work done by GARDS, GTLC and others. Discussion moved to specific areas for further action, such as the need for education of general practitioners and medical students; improved relationships between community advocacy and support groups, local healthcare providers and the Latrobe Regional Hospital; the need to continue to push for a memorial for SEC workers and others affected by asbestos disease; and the beginnings of a list of individuals, groups and organisations to whom the community would like the researchers to send a copy of this report.

There was agreement that the themes identified by the researchers did comprehensively outline community concerns, views and ideas for ways forward, and that the written report was ‘good’ (summarising written and oral feedback). However, several attendees at the community meeting felt that the report did not go far enough, describing it as ‘too tame’, ‘not as prescriptive as it should be’, and ‘lightweight—needs to be more concrete’. Many wanted more specific recommendations in the report, for example, on the healthcare services needed for asbestos disease sufferers, desired government/former SEC actions, and so on. However, we explained that our need as researchers was to stay focused on the two research questions, and that specific recommendations, for example on healthcare services required, could not be substantiated by the data collected for this study.

In summary, the meeting moved fairly quickly through the report’s findings (within an hour) to developing strategies for further action on identified themes (an additional hour), with relatively little input from the researchers on the latter. Given that the goal of the research was to capture community views on the issues and what could be done about them, and to build community capacity in this regard, we viewed the outcome of the meeting as a strong validation of our findings.

5

Conclusions and Future Directions

To conclude, we outline two overarching themes that we believe are most relevant to finding new and better ways to respond to the Latrobe Valley microcosm of Australia's on-going asbestos disease epidemic. First, a fundamental premise of public health—and the 'new public health' in particular—is that in addressing public health problems, the participation of those most affected in the formulation of a response is essential [16, 17]. This report demonstrates the need for substantial improvement in this regard as a first step. The lack of community participation is a major underlying theme throughout the narratives. Community members deserve a place at the table alongside government—as former employer and current protector of the public's health—and other stakeholders in the on-going formulation and implementation of responses to asbestos issues.

Second, the demonstrated social and emotional needs of people affected by asbestos disease and associated issues, and the void filled in this regard by the Latrobe Valley community, points to the need for social- and community-level responses to asbestos issues. Responses to date have been dominated by medical, scientific and legal concerns. While work in these areas is crucial and should continue, these efforts are primarily focused on the individual level. Furthermore, that focus is largely restricted to those directly affected by disease, leaving the indirect effects on the broader community unaddressed. Action and research on the social and community level impacts and responses should be expanded. Identification of specific areas for such efforts and corresponding intervention strategies should be developed with community participation. Examples distilled from Latrobe Valley interview narratives include: expanded efforts in social and emotional support; acknowledgment of, or apology for, past wrongs (valuable lessons in this area could be drawn from Aboriginal reconciliation efforts); compensation reforms; honouring the memory of asbestos disease victims; and building societal commitment for occupational disease prevention through community-based education and advocacy, government policy or other means.

Addressing the social and community-level impacts of asbestos disease in the Latrobe Valley—and other Australian and international communities—also has implications for the effectiveness of medical, legal and other interventions. Without some mutually acceptable way of acknowledging past wrongs, ways forward will be hampered. For example, smoking cessation is currently the only intervention known to reduce asbestos disease risks in exposed persons (significantly reduces lung cancer risk), and thus is the main intervention strategy in most asbestos worker programs. In the Latrobe Valley, however, progress in this area continues to be difficult due to the history of suppression of hazard

information and denial of asbestos-relatedness of disease, the lack of integration of the perspectives of smokers with asbestos exposures into programs, and inadequate consultation with key community groups on how smoking cessation programs might best be offered. As a second example, compensation reforms that erode claimants' rights and favour defendants (such as those currently proposed by the Australian asbestos supplier James Hardie) will most likely deepen community anger and resentment. Principles for finding solutions for projected liabilities that do not compromise the rights of those affected can be gleaned from recent US experience in this area [45, 46], wherein the US Congress rejected a proposed national trust statutory scheme. Finally, public participation in important on-going medical and scientific research would be optimised through restored trust and respectful communication with potential research subjects. Precedents in this regard are beginning to emerge around the world [18, 47].

In summary, this project suggests that asbestos issues would best be addressed by a comprehensive public and social health response with genuine community participation. We hope that this report goes some way towards building awareness of the need for healing at the community as well as the individual level, and that it helps to stimulate action in this regard. Only in this way can the Latrobe Valley—as well as other affected communities around the world—move on from this difficult aspect of our history and prevent similar occupational disease epidemics from happening in the future.

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