

**Submission
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INQUIRY INTO LOOSE FILL ASBESTOS INSULATION

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Contents

EXECUTIVE SUMMARY	2
INTRODUCTION.....	5
OVERVIEW OF THE AUSTRALIAN ASBESTOS EXPERIENCE.....	6
INTRODUCTION.....	6
ASBESTOS IN AUSTRALIA	7
HEALTH IMPLICATIONS	7
THE SOCIAL IMPACT OF A MESOTHELIOMA DIAGNOSIS	8
THE “DUSTED COMMUNITY”: UNDERSTANDING THE THIRD WAVE OF EXPOSURE TO ASBESTOS.	11
IMPLICATIONS FOR HOME OWNERS/OCCUPIERS EXPOSED TO LOOSE FILL ASBESTOS.....	12
LOOKING FORWARD: MANAGING THE POTENTIAL IMPACT OF THE THIRD WAVE	13
REFERENCES.....	14

EXECUTIVE SUMMARY

The focus of this submission is on the potential health and social implications of exposure to Mr Fluffy loose-fill asbestos for home owners and occupiers exposed to asbestos fibres in their homes; on the implications of environmental, rather than occupational exposure. The inhalation of asbestos fibres has been causally linked to a number of diseases including malignant mesothelioma, a rare tumour. The majority of research to date has focussed on understanding the epidemiology of this disease rather than on the social impacts of a diagnosis. There is a limited amount of predominantly European research into the experiences of older men exposed to asbestos in an occupational setting - the so-called first and second waves of exposure to asbestos. There is a lack of Australian research into the social impacts of mesothelioma in general, on women in particular and on people exposed during the 'third wave' of non-occupational, environmental exposures. Third wave exposures are relatively young, often in the prime of their working lives and with responsibility for young families. They include a significant proportion of women.

Recent Australian research suggests a steady and continual increase in the reported cases of malignant mesothelioma attributable to third wave exposures in Australia. In NSW rates of malignant mesothelioma in both men and women have risen steadily over the last 30 years and increasing numbers of non-occupational exposures are being reported. Compared to the occupational victims of the first and second waves of exposure, there is presently very little understanding about when, and at what level, mesothelioma attributable to the third wave of exposure might reach its peak.

A mesothelioma diagnosis is a catastrophic event. It is a debilitating disease characterised by a high symptom burden, rapid decline and death. As yet there are no reported cases of mesothelioma linked specifically to exposure to Mr Fluffy loose fill asbestos in NSW however both the Canberra Times and the ABC have reported the recent (mesothelioma) diagnosis of two Mr Fluffy homeowners. As a consequence the possibility of NSW homeowners or occupiers developing mesothelioma as a result of environmental exposure to loose-fill asbestos cannot be ruled out.

In addition to the debilitating symptoms associated with a diagnosis mesothelioma has a very significant social impact on the lives of those diagnosed and their carers. The main findings of recent Australian research into the social impacts of a diagnosis on men and women in NSW can be summarised thus:

- **The impact of a diagnosis on people exposed as part of the “third wave” of environmental exposures to asbestos is very different to the impact of a diagnosis on predominantly older men previously exposed to asbestos in the workplace.** Many people exposed to asbestos in their homes in NSW may not be eligible for workers compensation or support/services from the Dust Diseases Board. The medical costs associated with a diagnosis of mesothelioma can cause significant financial distress.
- **Mesothelioma has a significant negative impact on the well-being of carers.** Carers frequently experience social isolation as a result of the rapid deterioration of their loved one’s health. They provide constant care and support often at the expense of their own health, both physical and mental.
- **The consequences of a diagnosis on women within the emerging “third wave” community are complex and the least understood particularly where young children are involved.** Women who are unable to trace their exposure to a previous place of employment may experience severe financial disadvantage. Disadvantage is compounded for women living in regional Australia as access to specialist medical centres in Sydney frequently involves significant financial and personal cost.
- **Men and women with mesothelioma living in regional, rural or remote Australia experience additional disadvantage.** Travel to specialist treatment centres in Sydney places additional burdens on families already experiencing significant pressure. Lack of critical mass in regional centres also mitigates against the establishment of traditional support groups. This has an impact on the availability of information and advice.

The implications of these findings for homeowners and occupiers exposed to loose fill asbestos in their homes in NSW can be summarised thus:

- Homeowners/occupiers exposed to loose fill asbestos insulation and subsequently diagnosed with mesothelioma will form part of the emerging third wave of environmental exposures. This cohort is likely to be relatively young, (particularly if exposed during childhood), a percentage will be women and some will live in regional or rural Australia.
- Whilst our understanding of the social impacts of associated with a third wave diagnosis is still nascent research suggests that the members of this emerging community, particularly women and regional /rural Australians will experience additional, and sometimes multiple, disadvantage.

- It is likely that a proportion of this particular third wave cohort will **not** be able to establish any work-related exposure and will therefore be unable to access the services and support provided by the Dust Diseases Board. This lack of access will result in additional disadvantage.

Insofar as Australian initiatives designed to actively engage with the third wave cohort are concerned, the Dusted Community research project comprises a virtual, user-driven community of support and practice for people affected by an asbestos-related diagnosis and their carers, irrespective of the nature of their exposure to asbestos. The Dusted Community provides an opportunity to increase social connection and access to information and support.

Implementation of the next iteration of the Dusted Community (Phase 2) will begin in early 2015. Phase 2 has been designed in order to maximise understanding of the impact of diagnosis of mesothelioma on **the younger, third-wave cohort**, on women in general, and on the nature of regional disadvantage. It will have two key points of focus: as a **community of practice** for members; and, as a source of **knowledge** of the nature and needs of living with an asbestos-related disease.

In conclusion, the exposure of NSW homeowners and occupiers to loose fill asbestos insulation forms a significant part of the emerging third wave of environmental exposures. Government, at both a federal and state level, working in collaboration with other community stakeholders, has a key role to play in managing and mitigating the potential social economic and psychological impact of this next wave.

A thorough understanding of how and where the third wave might unfold is needed in order to increase the effectiveness of any future initiatives in NSW. Mapping and analysing the current delivery of support and services across NSW, including the awareness of key health professionals would enhance our collective knowledge. Initiatives and interventions designed to produce evidence of the priorities of men and women directly affected by the third wave of exposures will be equally as important. This knowledge, in combination with the mapping and analysis of existing services and support would enable gaps in the current provision of support and services, as well as areas of unmet need, to be identified and a range of appropriate responses developed. The establishment of a NSW asbestos research fund focussing on the short, medium, and long-term implications of third wave of exposures to asbestos would also enhance our understanding of the potential impact of a diagnosis. A key role of such a fund could be to encourage and promote innovative and interdisciplinary asbestos research collaborations between researchers, industry and community partners.

INTRODUCTION

This submission to the Joint Select Committee on Loose Fill Asbestos is made by Associate Professor Rick van der Zwan and Julie Tucker. It addresses section 1 (e) of the Committee's terms of reference namely "any other related matter" and draws on the authors' experience as Director of Research (Associate Professor Rick van der Zwan) and researcher (Julie Tucker) within the Regional Initiative for Social Innovation and Research (RISIR). RISIR is a multi-disciplinary research initiative currently based at the Coffs Harbour Campus of Southern Cross University (SCU).

Relevant experience includes the Asbestos Narratives Project (Bultjens, Cairncross, Kozlowski, Provost, Tucker & van der Zwan, 2014) delivered in 2013-2014 and funded by Comcare's Asbestos Innovation Fund (Wave 2). This research investigated the social, psychological and economic impacts of asbestos-related disease in Australia with a primary focus on the experience of men and women living in NSW. The final report was launched in March 2014 and is attached to this submission: see Appendix 1 The Asbestos Narratives Report has been cited during a (NSW) parliamentary subcommittee hearing into the future of the Dust Diseases Board of NSW (March 2014) and formed the basis of a cross-party workshop for NSW members of the Legislative Council in June 2014. The Asbestos Narratives Report has been used by asbestos organisations groups in England and Holland.

The Joint Select Committee has been asked to investigate and report on the implications arising from the use of loose fill asbestos, also known as "Mr Fluffy" in homes in NSW. At the same time this inquiry also takes place in the context of a much wider use of asbestos- containing building materials, particularly asbestos cement sheeting or "fibro", in the construction of homes in NSW during the housing boom of the 1950's. As a result many asbestos- containing building materials including insulation are still to be found in domestic residences throughout NSW (Park, Yates, Hyland & Johnson, 2013).

The use of loose- fill asbestos as a form of insulation raises a number of important issues pertaining to the identification and safe removal of this particular asbestos product. The focus of this submission however will be on the potential health and social implications of environmental exposure to loose fill "Mr Fluffy" asbestos.

Whilst recognising the risk of exposure faced by tradespeople and other professional working in or on houses containing loose fill asbestos as part of their employment this submission will concentrate

on the potential social and economic implications for the home owners and occupiers exposed to asbestos fibres while living in homes containing Mr Fluffy asbestos. In other words on the implications of environmental as opposed to occupational exposure. This is because the statutory framework for a person exposed to asbestos during the course of their employment is well established and managed in NSW by the Dust Diseases Board. Similarly the right to common law compensation is similarly established notwithstanding that case law is constantly evolving. By contrast there is no statutory framework in NSW for people whose exposure to asbestos was purely environmental.

The submission will comprise the following key areas:

- A brief overview of the Australian experience of asbestos including the health implications;
- The social impact of a diagnosis of malignant mesothelioma;
- Implications for homeowners/occupiers exposed to loose-fill asbestos;
- The “Dusted Community” : understanding the third wave of exposure to asbestos;
- Looking forward and actively managing the potential impact of the third wave.

OVERVIEW OF THE AUSTRALIAN ASBESTOS EXPERIENCE

INTRODUCTION

The link between the inhalation of asbestos fibres and malignant mesothelioma is well established and accepted. Whilst the epidemiology of mesothelioma has been the subject of significant research, both in Australia and internationally (Kanarek, 2011) the actual experience of living day-to-day with a diagnosis, for those diagnosed, their carers, and their family members has been under-researched. This relative lack of research represents a significant knowledge gap and one that is not easily filled by reference to the European experience, which takes place in a very different cultural and geographic context (Johnston & Mclvor, 2000).

In addition the majority of research to date has focussed predominantly on the experiences of older men, exposed to asbestos in an occupational setting - the so-called first and second waves of exposure to asbestos (Johnston & Mclvor, 2000). There has also been a paucity of research into the social impacts of mesothelioma on women and on people exposed during the ‘third wave’ of non-occupational exposures both here in Australia and internationally. The members of this third wave

cohort, often, although by no means exclusively exposed to asbestos during, or as a result of, home renovations and repairs, are relatively young, in the prime of their working lives and frequently have responsibility for young children. The third wave includes a significant proportion of women. (Olsen et al., 2011). Recent Australian research suggests a steady and continual increase in the reported cases of malignant mesothelioma attributable to third wave exposure in Australia (Olsen et al., 2011; KPMG, 2014).

ASBESTOS IN AUSTRALIA

Australia, like many countries worldwide has had a long and troubled association with asbestos. By the 1950's Australia had become the world's highest per capita asbestos user (among western nations) followed by the United States, the United Kingdom and France (Leigh et al. 2002). As a consequence asbestos has impacted significantly on the lives of many Australian men and women. Those affected include not only people who handled asbestos in their workplaces but also those who were inadvertently exposed in their homes, workplaces or communities.

There are three generally accepted "waves" of exposure to asbestos in Australia. The first wave of occupational exposure comprises those who worked in the asbestos mines and mills. This was followed by a second wave of occupational exposure experienced by employees in industries and trades where asbestos products were manufactured or extensively used, including power generation plants, the navy, shipbuilding and the railways. The third wave refers to non-occupational, environmental exposures. It includes people who are or will be potentially exposed to asbestos during home maintenance or renovation (Olsen et al., 2011) as well as people who have lived or worked in environments which contain embedded asbestos. Exposure occurs when the built environment deteriorates or is disturbed. This cohort of environmental exposures includes homeowners, teachers, scientists and other white collar workers.

HEALTH IMPLICATIONS

The inhalation of asbestos fibres has been causally linked to a number of diseases such as asbestosis, pleural thickening, pleural plaques, lung cancer, and malignant mesothelioma, a rare tumour. (Johnston and McIvor, 2000). Symptoms vary across the diseases, but usually involve coughing, pain, breathlessness, gradual disablement, and frequently death (Clayson, 2007; Hughes, 2006). Mesothelioma, the most common amongst the above, is particularly pernicious since it requires only a very brief exposure to asbestos (Williams, 2004), and death usually occurs within a year of diagnosis (Yates et al., 1997). In the past malignant mesothelioma affected mainly men however

increasing numbers of women with malignant mesothelioma are being reported (Hyland, Ware, Johnson & Yates, 2007).

Although the incidence of all asbestos-related diseases is not comprehensively documented, mesothelioma has been tracked closely for quite some time in some developed countries. Australia maintains a national register and has been recording its occurrence since 1980. According to Australia's National Health and Medical Research Council there have already been at least 4,700 deaths from mesothelioma in Australia since records began. An increasing trend of mesothelioma incidents from an average of 450-600 annual cases (between 1945 and 2000) to 680 in 2001 has been noted. The rate is expected to rise to 900 new cases per year by 2020 (National Health and Medical Research Council).

In NSW rates of malignant mesothelioma in both men and women have risen steadily over the last 30 years and increasing numbers of non- occupational exposures are being reported. (Hyland et al., 2007).

Significantly while the number of cases caused by occupational exposure is expected to fall post-2020 (Leigh et al., 2002; Phillips and Lindgren, 2010) other researchers warn that any decrease in occupational mesothelioma may be offset by the expected rise in non-occupational mesothelioma rates arising from the increase in DIY home renovation during the 1970's, 80's and 90's (Olsen et al., 2007). Recent media reports (e.g., Schmidt, 2013; Mirror, 2010; Globe, 2014; Canberra Times, 2014) and research findings (UWA, 2012) also indicate the vulnerability of a larger population of environmental exposures within the third wave of exposures. Compared to the occupational victims of the first and second waves of exposure, there is presently very little understanding about when, and at what level, mesothelioma attributable to the third wave of exposure might reach its peak.

THE SOCIAL IMPACT OF A MESOTHELIOMA DIAGNOSIS

A mesothelioma diagnosis is a catastrophic event. It is a debilitating disease characterised by a high symptom burden, rapid decline and death. These factors all contribute to feelings of isolation amongst patients and their families. Death due to disease is almost a certainty; leaving caregivers and families devastated and with high levels of persistent grief many years afterwards.

As yet there are no reported cases of mesothelioma linked specifically to exposure to Mr Fluffy loose fill asbestos in NSW. The situation is different in Canberra where loose-fill asbestos fibres were used

in at least 1050 homes. Both the Canberra Times and the ABC have reported the recent diagnosis of two Mr Fluffy homeowners (Canberra Times, ABC, 2014). As a result the possibility of NSW homeowners or occupiers developing mesothelioma as a result of environmental exposure to loose-fill asbestos cannot be ruled out.

In addition to the debilitating symptoms associated with a diagnosis mesothelioma has a very significant social impact on the lives of the men and women diagnosed and their carers. The main findings of previous research on the experience of men and women with an asbestos-related diagnosis in NSW and their carers (Buultjens et al., 2014) can be summarised thus:

The impact of a third-wave diagnosis is different

The impact of an asbestos-related diagnosis on men and women exposed as part of the “third wave” of environmental exposures to asbestos is very different to the impact of a diagnosis on older men previously exposed to asbestos in the workplace. One of the reasons behind this is that many people exposed to asbestos in their homes in NSW may not be eligible for workers compensation or support from the Dust Diseases Board.

In addition this third wave of environmental exposures includes a significant cohort of younger men and women, often in the prime of their working lives and with responsibility for younger children. A diagnosis results in an earlier loss of earning capacity and the attendant opportunity for social interaction. Younger partners may also become full time carers resulting in a further loss of earning capacity.

Impact on the well-being of carers

Mesothelioma has a significant negative impact on the well-being of carers. Carers frequently experience social isolation as a result of the rapid deterioration of their loved one’s health. They provide constant care and support often at the expense of their own health, both physical and mental. It would appear that carers may be at greatest risk of psychological distress, and most are in need of support services.

A number of carers commented on the support and services provided by the Dust Diseases Board. Services mentioned included lawn mowing, re-imburement of the cost of medications and the supply of oxygen and shower chairs. It should be remembered that these services are only available to people exposed to asbestos in the course of their work, the occupational exposures. The

jurisdiction of the Dust Diseases Board does not cover people whose only exposure to asbestos is environmental.

Women experience additional disadvantage

The impact of an asbestos-related diagnosis on women, whether as partners/carers or increasingly, as younger women with an asbestos-related diagnosis is significant. The consequences of an asbestos-related diagnosis on women within the emerging “third wave” community are perhaps the most complex and the least understood particularly where young children are involved. For women disadvantage manifests in many ways including the loss of career and financial independence.

Women who are unable to trace their exposure to a previous place of employment may experience severe financial disadvantage. Disadvantage is compounded for women living in regional Australia as access to specialist medical centres in Sydney can only be achieved at significant financial and personal cost.

The economic impact of a diagnosis is significant

The economic impact of a diagnosis of mesothelioma in NSW depends upon the circumstances in which exposure took place. A diagnosis of mesothelioma as result of previous exposure in a workplace can enable access to workers compensation payments and to the services and provided by the Dust Diseases Board. A diagnosis of mesothelioma caused solely by environmental exposure to asbestos does not. For those not covered by the Dust Diseases Board in NSW the medical costs associated with a diagnosis particularly mesothelioma can cause significant financial distress.

The potential for insurance companies to reduce liability on the grounds that previous exposure to asbestos constituted a pre-existing condition is another cause of financial distress.

A regional or rural diagnosis causes additional disadvantage

A regional or rural diagnosis has a number of implications, social, psychological and not infrequently, economic for people diagnosed, their carers and families. It is clear that travel to specialist treatment centres in Sydney places additional burdens on families already experiencing significant pressure including separation from local support networks. Lack of critical mass in regional centres also mitigates against the establishment of traditional support groups. This in turn has an impact on the availability of information and advice.

THE “DUSTED COMMUNITY”: UNDERSTANDING THE THIRD WAVE OF EXPOSURE TO ASBESTOS.

A diagnosis of mesothelioma frequently results in social isolation (Hughes & Arber, 2008). Those experiencing social isolation include the person diagnosed, their carer and sometimes other family members. Not just an unfortunate emotional consequence of facing the many challenges that come with a diagnosis, social isolation has robustly been associated with a wide range of suboptimal experiences and outcomes and, ultimately, with higher mortality (Wagner, 2007; Reblin & Uchino, 2008). At the same time a number of studies have shown that social support and increasing social connectedness can be protective for health (Reblin & Uchino, 2008).

Traditional, face-to-face asbestos support groups can provide geographically proximate members with a valuable opportunity for interaction and support however they are not readily accessible outside major population centres. In addition the acute symptoms of mesothelioma can make all forms of social interaction, including travelling to and attending a support group meeting difficult. Digital technologies and in particular online communities have the capacity to provide social support and thereby reduce the social isolation. Online communities also have the potential to connect members of this community to experientially similar others. They have an important role to play in Australia, a geographically large but relatively sparsely populated country characterised by a mix of urban, regional, rural and remote communities.

In 2013 the Dusted Community, a peer- to- peer online community for men and women affected by an asbestos-related diagnosis was established in consultation with potential beneficiaries as a pilot project within the Comcare- funded Asbestos Narratives Research. It was hoped that the Dusted Community, by addressing social support directly, would provide substantial benefits both for individuals with an asbestos diagnosis and for their carers.

Further consultation took place over a number of months in order to identify member needs and priorities. As a result the *Dusted Community* evolved into a supportive online environment where members could interact, learn from the experiences of others and offer and receive support from their peers. Members also identified the need for a separate carers’ space within the broader community.

The results of an evaluation conducted at the conclusion of the pilot phase (2013) revealed strong support for the online community amongst the community's founding members. Members emphasised the unique nature and challenges associated with an asbestos-related disease and the importance of being able to share their own stories (Kozlowski, Provost, Tucker, & van der Zwan, 2014).

Implementation of the next iteration of the Dusted Community (Phase 2) will begin in early 2015. Phase 2 has been designed in order to enhance our understanding of the impact of diagnosis of mesothelioma on **the younger, third-wave cohort**, on women in general, and of the nature of regional disadvantage. It will have two key points of focus: as a **community of practice** for members; and, as a source of **knowledge** of the nature and needs of living with an asbestos-related disease.

Significantly, Phase 2 will also see the full transition from an online community of circumstance to an online community of practice. Members will be encouraged to create their own digital content. They will be supported and enabled via access to an innovative digital literacy program designed to build digital skills and confidence.

IMPLICATIONS FOR HOME OWNERS/OCCUPIERS EXPOSED TO LOOSE FILL ASBESTOS.

The focus of this submission has been on the potential social impact of environmental exposure to loose fill "Mr Fluffy" asbestos. The implications for homeowners and occupiers exposed to loose fill asbestos in their homes in NSW can be summarised thus:

- Homeowners and occupiers in NSW who are exposed to loose-fill asbestos insulation and subsequently diagnosed with mesothelioma will form part of the larger third wave of environmental exposures to asbestos. This cohort is likely to be relatively young, (particularly if exposed to asbestos during childhood), a percentage will be women and some will live in regional, rural or remote Australia.
- Whilst our understanding of the social impacts of associated with a third wave diagnosis in Australia is still nascent, research suggests that the members of this emerging community, particularly women and regional /rural Australians will experience additional and on occasions, multiple disadvantage.

- It is likely that a proportion of this particular third wave cohort will **not** be able to establish any work-related exposure and will therefore be unable to access the services and support provided by the Dust Diseases Board.
- The Dusted Community research project is a virtual, user-driven community of support and practice for people affected by an asbestos-related diagnosis and their carers, irrespective of the nature of their exposure to asbestos. It provides an opportunity to increase social connection and access to information and support. In so doing it has the potential to inform both the future provision of services and our collective understanding of the social impact of a diagnosis of mesothelioma, particularly where this is the result of a third wave, environmental exposures.

LOOKING FORWARD: MANAGING THE POTENTIAL IMPACT OF THE THIRD WAVE

In conclusion, the exposure of NSW homeowners and occupiers to loose fill asbestos insulation forms a significant part of the larger third wave of environmental exposures. Government, at both a federal and state level, working in collaboration with other community stakeholders, has a key role to play in managing and mitigating the potential social economic and psychological impact of this next wave.

A thorough understanding of how and where the third wave might unfold is needed in order to increase the effectiveness of any future initiatives in NSW. Mapping and analysing the current delivery of support and services across NSW, including the awareness of key health professionals would enhance our collective knowledge. Initiatives and interventions designed to produce evidence of the priorities of men and women directly affected by the third wave of exposures will be equally as important. This knowledge, in combination with the mapping and analysis of existing services and support would enable gaps in the current provision of support and services, as well as areas of unmet need, to be identified and a range of appropriate responses developed.

In the short to medium term a series of practical collaborative projects around common issues would be of great value. For example, a collaboration designed to share information and expertise on issues pertaining to exposure to Mr Fluffy loose-fill asbestos between relevant departments in NSW and the ACT would help inform future policy and reduce the risk of duplication of resources.

Finally the establishment of a NSW asbestos research fund focussing on the short, medium, and long-term implications of third wave of exposures to asbestos would build on existing knowledge and enhance our understanding of the potential impact of a diagnosis. A key role of such a fund could also be to encourage and promote innovative and interdisciplinary asbestos research collaborations between researchers, industry and community partners. The research could also be used to drive a series of very practical community-based outcomes including education and awareness- raising programs in schools.

REFERENCES

ABC News (2014) Mr Fluffy: two cancer cases linked to homes with asbestos insulation minister says, ABC News, July 24 2014. Available at <http://www.abc.net.au/news/2014-07-22/two-mesothelioma-cases-linked-to-mr-fluffy-houses-minister/5613662>

Buultjens, J., Cairncross, G., Kozlowski, D Provost, S., Sen, S., Tucker, J., & van der Zwan, R. (2014) The Asbestos Narratives: A report into the real impact of an asbestos-related diagnosis on the lives of men and women and their carers.

Canberra Times (2014) Katy Gallagher says focus needs to be on a long-term Mr Fluffy asbestos insulation solution, Canberra Times, September 1, 2014. Available at <http://www.canberratimes.com.au/act-news/katy-gallagher-says-focus-needs-to-be-on-a-long-term-solution>.

Canberra Times (2014) Asbestos risk lingers as more Mr Fluffy home owners consider legal action, Canberra Times, April 14, 2014. Available at <http://www.canberratimes.com.au/act-news/asbestos-risk-lingers-as-more-mr-fluffy-home-owners-consider-legal-action-20140413-36lqu.html>

Clayson, H. (2007). The experience of mesothelioma in northern England. Unpublished MD thesis. Academic Unit of Supportive Care: University of Sheffield, UK. Available at: <http://etheses.whiterose.ac.uk/id/eprint/1775>

Globe (2014), No safe use, Globe, June 17, 2014. Available at:
<http://www.theglobeandmail.com/report-on-business/no-safe-use-as-the-top-workplace-killer-asbestos-leaves-a-deadly-legacy/article19151351/>

Hughes, N. (2006), The first time I told my story. A phenomenological study of the lived experience of mesothelioma. Unpublished Msc Dissertation, University of Surrey: Guildford, UK.

Hughes, N. and Arber, A. (2008), The lived experience of patients with pleural mesothelioma. *International Journal of Palliative Nursing* 14(2):66–71.

Johnston, R. and McIvor, A. (2000), Pushed into social exclusion: asbestos-related disability and relative poverty on Clydeside. *Scottish Affairs Summer* 32, pp: 95-109.

Kanarek, M. (2011), Mesothelioma from Chrysotile Asbestos: Update, *Annals of Epidemiology* 21(9):688-697.

Kozlowski, D., Provost, S., Tucker, J., and van der Zwan, R. (2014). Dusted community: piloting a virtual peer-to-peer support community for people with asbestos-related diagnosis and their families. *Journal of Psychosocial Oncology*. 32(4), pp 463-475.

KPMG (2014) Valuation of Asbestos-related disease liabilities of former James Hardie entities to be met by the AICF trust.

Leigh, J., Davidson, P., Hendrie, L. and Berry, D. (2002), Malignant mesothelioma in Australia, 1945-2000. *American Journal of Industrial Medicine* 41(3):188-201

Olsen, N., Franklin, P., Reid, A., Klerk, N., Threlfall, T., Shilkin, K. and Musk, B. (2011), Increasing incidence of malignant mesothelioma after exposure to asbestos during home maintenance and renovation. *Medical Journal of Australia* 195(5):271-274.

Park, E K., Yates, D., Hyland, R., and Johnson, A. (2013), Asbestos exposure during home renovation in NSW. *Medical Journal of Australia* 199 (6):410 – 413.

Phillips, G. and Lindgren, M. (2010), The Australian Asbestos Network – how journalism can address a public health disaster. *Observatorio Journal* 4(4):197-213.

Reblin, M., and Uchino, B. (2008). Social and emotional support and its implications for health. *Current Opinion in Psychiatry*, 21, pp.201-205.

Schmidt, L. (2013), 'Third wave' of asbestos victims diagnosed. Illawarra Mercury 19 June 2013. Available at: <http://www.illawarramercury.com.au/story/1582279/third-wave-of-asbestos-victims-diagnosed/> (retrieved) 30 October 2013.

UWA (2012), Deadly asbestos takes toll years after kids exposed. University News 3 September 2012, University of Western Australia. Available at: <http://www.news.uwa.edu.au/201209044978/research/deadly-asbestos-takes-toll-years-after-kids-exposed> .

Wagner, G. R. (2007). The fallout from asbestos. *Lancet*, 369(9566), 973-974. doi: 10.1016/S0140-6736(07)60472-3

Williams, S. (2004). The long goodbye. *The Guardian*, 18 October 2004. Available at: <http://www.theguardian.com/society/2004/oct/18/medicineandhealth.lifeandhealth> (retrieved 10 October 2013).

Yates, D. H., Corrin, B., Stidolph, P. N. and Browne, K. (1997). Malignant mesothelioma in south-east England: clinicopathological experience of 272 cases. *Thorax* 52(6):507-512.