



THE ASBESTOS NARRATIVES:

A REPORT INTO THE REAL IMPACT OF AN
ASBESTOS-RELATED DIAGNOSIS ON THE LIVES
OF MEN AND WOMEN AND THEIR CARERS

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RESEARCH COLLABORATIONS:

This research project was funded through the Comcare Asbestos Innovation Fund (Wave 2) and was undertaken by researchers from the Regional Initiative for Social Innovation and Research (RISIR), a research initiative of Southern Cross University. The project team worked in partnership with specialist online community designer and project partner vTeam, with the Sydney office of Slater & Gordon's Civil Liabilities Practice and with the Asbestos Diseases Foundation of Australia (ADFA).

Over 60 people, both men and women, shared their experiences of living with an asbestos-related diagnosis and stories during the course of this research. The value of their contribution to the knowledge generated by this research cannot be underestimated.



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- Mike O'Donnell, Public Officer, Asbestos Diseases Foundation of Australia Inc. (ADFA);
- Barry Robson, President, ADFA;
- Mort Shearer, Board Chair, Lifeline Mid North Coast;
- Joanne Wade, State Practice Group Leader, Civil Liabilities, Slater & Gordon.

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NEW KNOWLEDGE

**DANGER
ASBESTOS**



**DANGER
ASBESTOS**



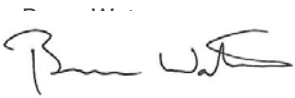
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FORWARD

Southern Cross University's project to understand the social, psychological and economic impacts of asbestos-related disease was one of fourteen projects to receive funding through the Asbestos Innovation Fund. The Fund was established in 2010 by the Australian Government in an effort to raise awareness about asbestos, assist in the management and removal of asbestos, as well as improve the treatment and support available for asbestos-related disease sufferers and their families.

The multidisciplinary team of researchers from Southern Cross University's Regional Initiative for Social Innovation and Research (RISIR) has provided new insights and evidence into the social, psychological and economic impacts of asbestos-related disease in this report. It draws together the contribution of the project's partner organisations and the experiences of over sixty men and women who have been affected by asbestos exposure in some way. While historically asbestos-related disease research has predominantly focused on men, this research also focused on women who have been diagnosed with asbestos-related disease, and on women as carers, providing new and informative insights into how this debilitating disease impacts and affects women.

It has been a pleasure working with Southern Cross University. The Asbestos Innovation Fund Assessment Committee would like to thank them for their efforts to improve the outcomes for Australians affected by asbestos-related disease. It is hoped that this report will not only generate much interest and discussion, but that it will also contribute to the discussion around the policies and strategies to raise public awareness about asbestos, and improve the treatment and support available for asbestos-related disease sufferers and their families.



Chair, Asbestos Innovation Fund Assessment Committee
Executive General Manager, Claims Management and Insurance, Comcare



EXECUTIVE SUMMARY

Significant research exists about the epidemiology of asbestos-related disease. Far less is known about the real impact of an asbestos-related diagnosis on the lives of men and women and their Carers. This report highlights the key findings of the Asbestos Narratives, a research project funded through the Comcare Asbestos Innovation Fund. A multidisciplinary team of researchers from Southern Cross University's Regional Initiative for Social Innovation and Research undertook this project.

This project was designed to give voice to the many communities affected by exposure to asbestos, to document their experience, and to enable a better understanding of the social, psychological, and economic impact of an asbestos-related disease. The project had a particular emphasis on the impact of an asbestos-related disease on women; both women diagnosed with an asbestos-related disease and women as Carers. The goal of the project was to inform policy makers, organisations, and professionals especially around the future provision of services and support.

THE ASBESTOS NARRATIVES COMPRISED THREE RESEARCH INITIATIVES:

- Quantitative data as to the impact of an asbestos-related diagnosis on psychological well-being was collected via a survey comprising a series of standardised instruments;
- Qualitative data was generated through

- a series of semi-structured interviews exploring the social and economic issues associated with a diagnosis;
- A peer-to-peer online community for people affected by an asbestos-related diagnosis and their Carers was established in order to test the efficacy of a virtual support model.

Researchers spoke to men and women with an asbestos-related diagnosis and to Carers, both current and past. This research focussed on the experience of people currently living in NSW but incorporated the experiences of number of people living in regional Queensland. This report highlights key findings from within and across the three research activities:

CARERS:

The significant negative impact of an asbestos-related diagnosis on the well-being of Carers emerged from each of the three research activities. In addition to coming to terms with the various health implications of a diagnosis, Carers when interviewed spoke of the devastating social impact of a diagnosis, of normal lives suspended. Past Carers reflected on the personal cost of caring. They spoke of providing constant care and support at the expense of their own health, both physical and mental. The quantitative research also indicates that Carers may be at greatest risk of psychological distress, and most are in need of support services.

WOMEN: the impact of an asbestos-related diagnosis on women, whether as Carers or increasingly as younger women with an asbestos-related disease, is significant and complex. For women with a diagnosis disadvantage manifests in many ways including the loss of career and financial independence. In NSW women exposed to asbestos in non-occupational settings may not be eligible for the support and services provided by the Dust Diseases Board and may face severe financial hardship as a result.

SERVICES AND SUPPORT NETWORKS:

The importance of support from friends and family, social networks and asbestos support organisations emerged as a significant theme across the research. The value of the practical support and various services provided by the Dust Diseases Board was frequently cited by those eligible to receive these services. Similarly, access to accurate and competent advice, both legal and medical was seen as a critical moderator of the impact of a diagnosis.

ECONOMIC IMPACT:

The economic impact of an asbestos-related diagnosis is multi-layered. Early retirement has both a social and an economic impact and the medical costs associated with a diagnosis can cause significant financial distress for those not covered by the Dust Diseases Board in NSW.

REGIONAL IMPACT:

A regional 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.

THE ROLE OF A PEER-TO-PEER ONLINE COMMUNITY PROJECT

participants expressed strong support for an on-line community and emphasised the unique nature and challenges associated with an asbestos-related disease during the interviews described above. This was especially so for women.

The findings of this research and in particular the gaps identified in the current provision of services and support provide real insights into the psychological, social and economic impacts of an asbestos-related diagnosis. They also have significant implications for future research. A clearer understanding of the impact of an asbestos-related diagnosis on the younger, third-wave cohort, on women in general and on the nature of regional disadvantage will inform the future development and delivery of the services and support needed to respond to the ongoing challenge of exposure to asbestos in Australia.

LOSS OF SOCIAL SUPPORT CAN CONTRIBUTE TO FEELINGS OF ISOLATION THAT MAY ALREADY HAVE BEEN PRESENT, ESPECIALLY GIVEN THAT PATIENTS TEND TO RESTRICT THEIR NORMAL ACTIVITIES INDEED, ONE OF THE KEY PSYCHOSOCIAL COSTS OF AN ASBESTOS-RELATED DISEASE, BOTH FOR THE INDIVIDUAL WITH THE DISEASE AND FOR THEIR CARER, IS THE SENSE OF BEING SOCIALLY ISOLATED.



REPORT

WHAT WE DID AND WHY

INTRODUCTION

"It slows you down yeah. You are weak, I try & go for a walk everyday but I started getting pain this year. You can't do much you're weak. We try & go on holiday were you don't have to walk around & sitting around & that sort of stuff. Been to Hamilton Island same thing you fly in, go up to the apartment & don't do much. You can't do anything like you used to do."

"You know one of the hardest things I find is? If I go up to the mirror now and see me it doesn't look like there is anything wrong with you. I look fine. You can't see it. You can't see this disease."

The epidemiology and biology of asbestos-related disease, particularly mesothelioma has been the subject of significant research, both here in Australia and internationally. By contrast the actual experience of living day-to-day with an asbestos-related diagnosis has been under-researched and is thus poorly understood.

Similarly, whilst a number of studies have examined the physical impact of a diagnosis, fewer have focused on the social, psychological and economic implications of an asbestos-related disease on the lives of those diagnosed, their Carers and family members. Notwithstanding Australia's long and troubled association with asbestos very few studies have examined the impact of an asbestos-related diagnosis within an Australian context. This represents a

significant knowledge gap. The European experience, whilst relevant, takes place in a very different context.

Unsurprisingly the experience of living with an asbestos-related disease in regional Australia has also been under-researched. Similarly, there is little understanding of the impact of a diagnosis on women and men affected by exposure to asbestos during home renovations or repairs, the so called "third wave" of asbestos-related exposure. The Asbestos Narratives was designed to give voice to the many communities affected by exposure to asbestos, to document their experience and to enable a better understanding of the social, psychological and economic impact of an asbestos-related disease. The project had a particular emphasis on the impact of an asbestos-related disease on women; both women diagnosed with an asbestos-related disease and Carers and employed a combination of quantitative and qualitative research methodologies.

The qualitative research component comprised the use of semi-structured interviews designed to encourage project participants to tell their own stories. This process has yielded insight into the nature and extent of social and economic disadvantage experienced by men and women affected by exposure to asbestos. Quantitative data as to the psychological impact of an asbestos-related diagnosis has been collected via a questionnaire comprising a number of validated instruments.

The final element of the research has been the creation of the Dusted Community, a peer- to- peer online community for men and women affected by an asbestos-related diagnosis. Addressing social connectedness directly may have benefits both for individuals with an asbestos diagnosis and for their Carers. This research investigated the potential of an online community to provide support, friendship, information and a sense of belonging to a wider community.

¹ By the 1950's Australia had become the world's highest per capita asbestos user (among western nations) 1950s followed by the United States, the United Kingdom and France (Leigh et al. 2002).

CARERS NEED

SUPPORT

Carers of people with an asbestos-related diagnosis, be they partners or other family members, experience substantial disruptions in their life. Partners and family struggle to balance new responsibilities of caring along with the daily chores of family life. As one past carer said ...

“There was nothing else other than hospital appointments and stuff like that...there is no life...it just stopped...It nearly broke me as well... I wasn't eating or sleeping...it was 24/7 care, and even when he was asleep, I would be laying there watching him.”

The psychological impact on this group is striking too. Some isolated themselves after seeing their near and loved ones **fade away before (your) eyes**.

Feelings of loneliness, anger and depression were observed. One of the Carers candidly reported her story saying ...

“Some days I am terrific I can talk about it and other days I just can't. I feel like smashing things...I think it has been a grieving process and it has changed our lives.

Another added,

“Sometimes I would love to talk to someone and just get stuff out of my chest and have a really good whinge and then just move on.”

Towards the end, the life of a carer may simply... **revolve around the food as you have to keep them eating but it is so hard to do sometimes.**

Very few of the Carers interviewed, current or past had sought or received professional support or services.



BEYOND BEING MERELY AN UNFORTUNATE EMOTIONAL CONSEQUENCE OF FACING THE CHALLENGES THAT COME WITH AN ASBESTOS-RELATED DIAGNOSIS, FEELINGS OF SOCIAL ISOLATION HAVE ROBUSTLY BEEN ASSOCIATED WITH A WIDE RANGE OF SUB-OPTIMAL EXPERIENCES AND OUTCOMES AND, ULTIMATELY, WITH HIGHER MORTALITY.

WHAT WE DISCOVERED

An asbestos-related diagnosis, particularly mesothelioma is a catastrophic event. As one of the project's interviewees remarked:

"And given the type of disease, there is no cure – it is a terminal disease. It is not like others. There is no cure. When you are diagnosed – you are diagnosed. There is no escaping it – no curing it."

Interviewees diagnosed with other asbestos-related diseases spoke both of a sense of relief, i.e., that the diagnosis was not mesothelioma, but also of their fears for the future.

"I look at myself as being fairly lucky – I have only got pleural fibrosis. Oh it does (have an impact on your life) – it is just not going to kill you as quick."

This project has created new knowledge as to where, why and how disadvantage affects people with an asbestos-related diagnosis and their Carers.

Research has been generated across three separate but interconnected types of disadvantage, psychological, social and economic. The picture emerging is one of several distinct, but related communities each facing multiple challenges, simultaneously.

Within the "dusted" community several sub- communities, men with a diagnosis of mesothelioma, men with a diagnosis of pleural plaques, men and women previously exposed to asbestos but not diagnosed, women with a diagnosis,

Carers (current and past) and increasingly, younger people affected by "third wave of exposure" all co- exist. Significantly, women form a substantial proportion of this emerging, third wave community.



"AT THE TIME WE HAD NOBODY. THERE WAS NOBODY IN [OUR REGIONAL TOWN] WITH MESOTHELIOMA OF ANY TYPE AND NONE OF THE DOCTORS KNEW ABOUT IT."

- CARER

THE THIRD WAVE OF EXPOSURE TO ASBESTOS IS DIFFERENT

The impact of an asbestos-related diagnosis on men and women exposed during home renovations and repairs, as part of the “third wave” of exposure 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. This support makes a **huge financial difference.**

The social impact of a third wave diagnosis is also different. It was noted that *... giving up work and retiring early when he wanted to go on working for as long as he could ...* was hard for a man nearing retirement. For younger people this loss of earning capacity and the opportunity for social interaction occurs much earlier. Responsibility for the care of young children adds another dimension. One younger woman with a diagnosis and four young children described herself as someone living... **a parallel life... wife, mum, home person and then I am a (meso) patient.**

The statement *... I can't really relate back to them* probably best summarises the inherent differences between older men with a diagnosis and this younger emerging community of third wave exposures.

KEY FINDINGS: CARING FOR THE CARERS

“As for their families I think it hits the families even more I really do. They are there when they are diagnosed they go right through the whole process.”

“It's hard on her. I'm a drain on her. I can't go upstairs. I'm down here all the time. I've made sure she is well looked after if I go.”

A major finding of both the quantitative and qualitative research has been the multi-faceted impact of a diagnosis on Carers and the crucial role played by extended networks of social support in ameliorating disadvantage.

The devastating impact of an asbestos-related diagnosis extends far beyond the person diagnosed. Family life is irrevocably altered and partners, previously wives but increasingly, husbands become Carers. In addition to coming to terms with the various health implications of a diagnosis, Carers when interviewed spoke of the devastating social impact of a diagnosis, of normal lives suspended.

“You know, your day revolves around taking the medication in the morning, your Doctor's appointments, your tests, your this, your that – there was nothing else other than hospital appointments and stuff like that. There is no other life. It just stopped!”

“That is right – we were planning for retirement the whole time we were together. Because we used to sit over there and we used to say we were going to go back packing around Australia and his friends used say we would get from one Hilton to the other. “

Past Carers reflected on the personal cost of caring. They spoke of providing constant care and support at the expense of their own health, both physical and mental.

“It was a very big responsibility. It was. It nearly broke me as well.” “I was half the size I am; I was as white as a ghost. I had big black rings under my eyes and I didn't realise it at the time how terrible I looked. I wasn't eating or sleeping. It was 24/7 care and even when he was asleep I would be laying there watching him to make sure his chest was still going up and down.”

On the whole current Carers, those still in the midst of caring for a loved one spoke less freely about the personal cost of caring. However some still made some reference to the impact of this new responsibility on their lives:

“I go through days & this is a bad day. Its dramatic we thought we'd hit a brick wall, what's happened. We had just come to that part of our lives where I had just retired & I was working 4 day per week. I was going to cut down to 3 for another 6 months & retire then go on our merry way. Everything was rosy & then everything was put on hold. Of course I gave up work right away. He is tough he is very strong mentally I'm hopeless. Some days I'm terrific I can talk about it & other days I just can't.”

“I can't see me working. I would love to work in Leisure and Lifestyle. It is like I have gone through my life and I have actually found something that inspires me. Huge satisfaction! But there are just things [sigh]..... I suppose itI don't think I have accepted being on... I don't know if I could cope working full time. I couldn't.”

Significantly whilst a number of Carers commented on the importance and value of the support and services provided by the Dust Diseases Board none appeared to be in receipt of any support tied directly to their own needs. One carer spoke movingly of the impact of having support withdrawn

upon the death of her partner:

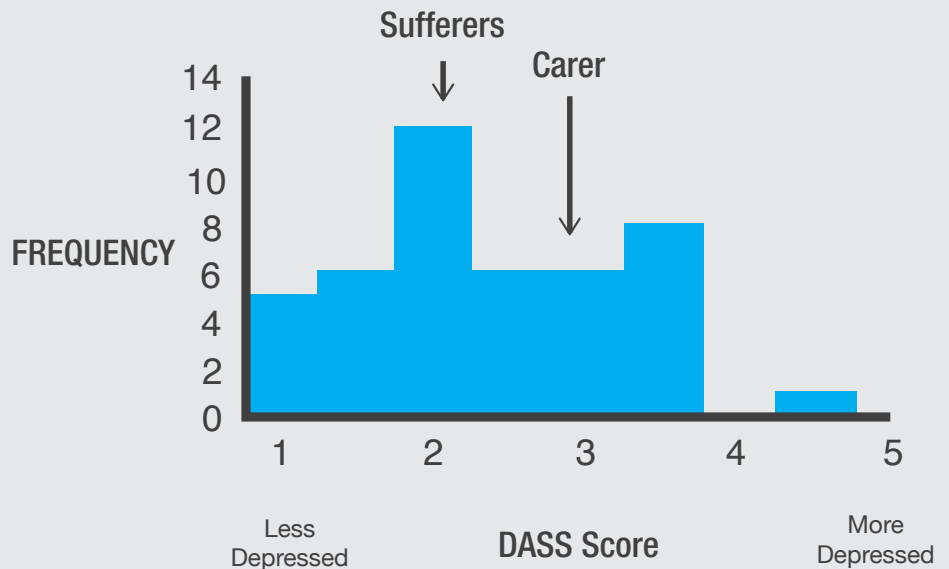
“They don’t even give you time to get replacement people to come in – from that very instant, everything is cancelled – you are on your own. Not even a week to get a replacement, to get your head together. Like and to, at that time you are dealing with major, major dramas. Apart from the funeral (because they paid for the funeral) apart from that, everything else stopped right at that day, until everything went to the board and everything.

But all of that was all cancelled – from that very minute... There was no notice. It was just instantly cancelled. Everything finished. “

Those reflections are not just anecdotal. The quantitative research shows clearly the impact on Carers of looking after someone with a diagnosis of asbestos disease. For example, and paradoxically, those without a diagnosed disease (mostly women and mostly Carers) were significantly more depressed than those with a disease diagnosis – Graph 1.

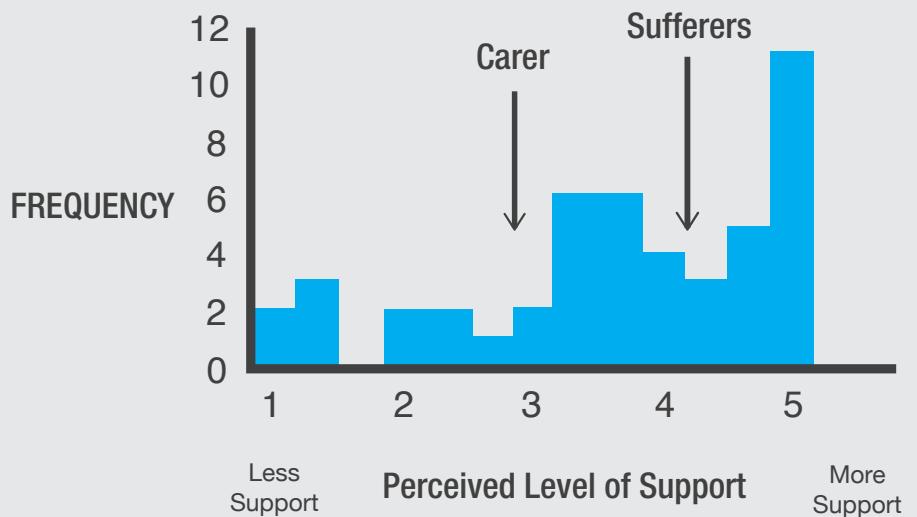
Similarly, those without a diagnosed disease (mostly women and mostly carers) perceived themselves to have significantly less social support from somebody special than those with a disease diagnosis – Graph 2. In other words, Carers are most at risk of falling victim to psychological distress and most in need of active and on-going support.

These two findings have provided evidence in support of the third component of this research, the Dusted Community an online, peer-to-peer community for people affected by an asbestos-related diagnosis. This community, whilst still in its early stages has already yielded valuable insights into the need for social connection, particularly amongst Carers both current and past.



GRAPH 1:

Scores on the Depression Anxiety Stress Scale (DASS) for all participants. The average DASS score reported by Carers was 2.9 ± 0.22 (right arrow). The average level for those with a diagnosis was 2.3 ± 0.19 (left arrow). Those with a diagnosed disease (mostly men) were significantly less depressed than those without a diagnosis (mostly women and mostly Carers: $t_{42} = 2.1, p = 0.04$).



GRAPH 2:

Scores on the Perceived Social Support scale for all participants. The average level of perceived support reported by Carers was 3.0 ± 0.37 (left arrow). The average level for those with a diagnosis was 4.3 ± 0.21 (right arrow). Those with a diagnosed disease (mostly men) felt significantly more support from somebody special than those without a diagnosis (mostly women and mostly Carers: $t_{42} = 3.4, p = 0.002$).

ASBESTOS, DISADVANTAGE AND WOMEN

"I think because I had the kids and they were young obviously, so life had to pretty much still keep going for them if nothing else."

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, multi-faceted. 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 with a diagnosis disadvantage manifests in many ways including the loss of career and financial independence:

"I planned that when my youngest was at school I would go back to work - but when she was three that is when I was diagnosed and that kind of put a spanner in the works. So I never ended up going back to work and I am still a stay at home mum."

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.

"I know another lady who I have recently met (who is 40) she has just finished everything now. She has had the chemo, operation and radiotherapy. She has

three little kids. The Dust Diseases Board cannot help her as she is a teacher and there is exposure obviously somewhere but her parents renovated when she was little and her story is similar to mine where she was about seven or eight. But there is no place at work she can ever remember. Even as a teacher, there is nothing there for her... She can't remember anything work related so she hasn't been financially covered and I know it has been a big burden on her. She lives at Bathurst so for her treatment she has had to come here and stay for a week, so I am guessing there are accommodation costs etc."

Children provided both a very significant additional challenge and a mechanism for coping.

"That was my number one and still is. It is always how is this going to impact on the kids and how will this traumatise them in the long run and how are they going to get through it - and F was the same. Let's just try and keep going and keep life as normal. So he went to work as normal."

MAKING A DIFFERENCE TO PEOPLE'S LIVES: SERVICES AND SUPPORT NETWORKS

"I'm very lucky with the neighbours next door if I don't wind up my venetian blind in the morning he is there looking for me."

The importance of support from friends and family, social networks and asbestos support organisations emerged as a significant theme across the research.

"It is isolating because I can't get out. Our neighbours & church friends have been very good and family. That's another thing family are so important."

"Yeah ADFA have been terrific.... Any problem you have any questions or problem they sort it all out & the Dust Board has been really good with us."

The value of the practical support and various services provided by the Dust Diseases Board and the caring, professional attitude of frontline staff was frequently cited by those eligible to receive these services.

"Well I have been lucky as I get help from the Dust Diseases Board. Luckily, financially that is one thing at least I can't say I have had a problem with. Financially I have been covered as the Dust Diseases Board has reimbursed me for everything. So I am not out of pocket."

"The Dust Board has been really good with us. When M needed the oxygen I rang the Dust Diseases Board & there is a girl K, she looks after us. I told her we needed the gas & she said I will send a letter straight through to your Doctor She did that & the Doctor must have sent it straight back to her because the next day we had the gas on the door step. They delivered it from Sydney. Then the same thing happened with this shower chair. I rang up about the shower chair & I think we had it 2 days later. So it's terrific how they do that for you & she kept saying is there anything else you want"

SUPPORT NETWORKS MATTER

The role of support networks in the life of people with an asbestos related diagnosis and their Carers appeared to be immense. Support from family and friends minimised the feelings of isolation and frustration from being unable to lead a normal life.

While one of the participants expressed her relief stating **we got an email from my husband's soccer mates asking if he could come and visit...and I would say yes by all means**, others considered themselves lucky to have family, friends and neighbours who sent food, offered to share daily responsibilities such as dropping the kids to school, and came together to stand by them during the periods of crisis.

External support played a different but nevertheless important role. The DDB in NSW, for example, assisted patients in many ways. One of the Carers stated **...they (DDB) provide anything that I couldn't do**. The services provided by the Dust Disease Board include transport to treatment, the provision of oxygen cylinders, cleaners and home handymen.

The value of the support provided by asbestos support organisation ADFA, frequently the first contact point for the newly diagnosed was also highlighted.

THE ECONOMICS OF AN ASBESTOS-RELATED DIAGNOSIS

"I honestly don't know how they (people not covered by the Dust Diseases Board) do it... Like if it wasn't for the Dust Diseases Board reimbursing us for medications and travel, things like that – we would have gone under financially – and we were pretty well set up and we would have gone under. Not a doubt in this world! ...I would be putting in \$200 - \$300 \$400 medical bills just for prescriptions and medications regardless of anything else. Like monthly! And I am talking monthly! You wouldn't come out of the chemist without it costing \$100 you know?"

"Oh I would have been working until I was 65. I still would have been at work now with another two or three years to go. I didn't want to retire until I was 65."

The economic impact of an asbestos-related diagnosis in NSW is complex. On one level it is determined by the type and

circumstances surrounding of diagnosis. 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 pleural plaques does not. Nor does a diagnosis of mesothelioma caused solely by exposure to asbestos in the home. 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:

"I know another lady who I have recently met (who is 40) she has just finished everything now. She has had the chemo, operation and radiotherapy. She has three little kids. The Dust Diseases Board cannot help her as she is a teacher and there is exposure obviously somewhere but her parents renovated when she was little and her story is similar to mine where she was about seven or eight. ...She can't remember anything work related so she hasn't been financially covered and I know



RESEARCH SHOWS THAT CONTACT WITH “EXPERIENTIALLY SIMILAR OTHERS” CAN BE EXTREMELY IMPORTANT IN TERMS OF SOCIAL SUPPORT AND COPING. BENEFITS INCLUDE IMPROVEMENTS IN PERCEIVED PERSONAL SELF-CONTROL, ALLEVIATING TENSION, AND PROVIDING VALUABLE ROLE MODELLING IN COPING.

it has been a big burden on her. She lives at Bathurst so for her treatment she has had to come here and stay for a week, so I am guessing there are accommodation costs etc.”

Other less obvious forms of economic impact were also highlighted including loss of long service leave entitlement.

“And he said “I can’t work no more... This particular day he came home and said “I have had it” so we were three weeks off the ten years that you get your money. And they never paid him. No...”

A number of Carers also spoke of difficulties encountered when claiming welfare benefits, particularly benefits associated with their roles as Carers. There appeared to be a lack of understanding about the level of care involved in looking after someone with an asbestos-related diagnosis. The process of making a claim was also seen as unnecessarily complicated and demeaning.

“Um, no I hated it and I felt like a second or third class citizen and I really started to feel and understand what people who are unfortunate enough to be unemployed because of a cycle thing or whatever – and anyway we got through that. Dr D our GP was brilliant - supported us. I still had no understanding, what do I do?”

“So people are missing out? I very much believe in advocacy and I think there should be more of that for people. I was lucky that I have a working life where I have had to make decisions and be confident ... but there would be people that would throw their hands up very easily.”

The potential for insurance companies to deny liability on the grounds that previous exposure to asbestos constituted a pre-existing condition was also identified:

“And another thing while I am thinking of this, we had a life insurance policy. It was denied because it was classed as an existing disease – which in theory was right – but when we signed up for the life

insurance, we had no idea that he was going to be diagnosed with mesothelioma Unless you have actually had your life insurance policy for 30-40 years (before you got the disease or are exposed to it) you are denied because they class this as an existing condition.”

THE IMPORTANCE OF PLACE: THE IMPACT OF A REGIONAL DIAGNOSIS

“Yeah.....it was a ride. As I said back and forwards to Sydney every couple of months and staying at Bezzina House and like the second operation we had to stay down there for three weeks because they wouldn't let him fly or anything ...”

A regional 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.

“T lives at Bathurst so for her treatment she has had to come here and stay for a week... She has found it particularly difficult because of the travel. She did it so much more tougher than me It is a specific radiation treatment they use and is only at RPA for Meso. So she was having to stay down here Monday to Friday for six to seven weeks. I don't know if her husband stayed with her but I presume she had to have someone staying with her – but as you say, being away from her family and the cost?”

Lack of critical mass in regional centres mitigates against the establishment of traditional support groups. This in turn has an impact on the availability of information and advice.

**MEMBERSHIP OF AN ON-LINE PEER-TO-PEER SUPPORT GROUPS
HAVE BEEN FOUND TO ENGENDER A SENSE OF SOCIAL COHESION
AND TO PROMOTE FEELINGS OF EMPOWERMENT.**

IT'S HARDER IN THE REGIONS

Living with a diagnosis in regional locations was found to have serious implications. Some interviewees needed to go to nearest metropolitan centres to meet their lawyer while others were referred to hospitals in Sydney for tests.

Given the poor health condition of the patients, the travel involved was often... **too much of a drive for some**, while others thought it was a **pain in the neck**. Those who had to frequently visit medical centres in bigger cities for treatment purposes were even more affected. They mainly complained ... **not many (local) hospitals have cancer wards**, and even those that had, did not have the required medical facilities and adequately trained staff to look after people with an asbestos-related diagnosis. The experience of local hospitals could also be problematic... **Oh! He had a terrible time at (the local) RPA... he was complaining about his knee and leg...and she (doctor) still signed him out....it was shocking**. Another past carer, who had to stay away from home and family members on a number of occasions for prolonged periods of time also expressed her frustration saying ... **that was our whole life**.

Other issues that emerged from the data include financial costs, lack of support, and awareness in regional areas.

One of the Sydney participants, for example, expressed her sympathy for a Bathurst patient knowing that**it has been a big burden on her... for her treatment she has to come here and stay for a week**. Others noted the lack of support groups in regional locations. A disparity in asbestos awareness was noted as one stated... **people in the city know about it (mesothelioma), but in the country, they don't know anything**.



THE DUSTED COMMUNITY: INCREASING SOCIAL CONNECTION

"I think it is a great idea. Sufferers and their families need vindication. They need to tell their stories."

Although it is still early days the Dusted Community has already increased our understanding of the potential of a peer-to-peer virtual community to offer support to individuals with an asbestos-related disease and their families. Project participants expressed strong support for the on-line community concept and emphasised the unique nature and challenges associated with an asbestos-related disease. This was especially so for women.

"I know talking to other patients is that they found it hard because they could not find others to relate to, but when you go to a cancer support group it is mainly breast cancer or lung or other different types cancers - but not specifically mesothelioma - so they wouldn't get a lot out of going to those support groups as they couldn't relate."

"I think would be very beneficial and something where other mesothelioma patients could connect and get together and just share their experiences - and say:

- This is what I have been going through and I have had this symptom, is it normal?*
- Have you gone through that?*
- I am not liking that food any more. Just things like that.*

I think that would be really good. If nothing else comes out of it I think some sort of support group or social network like that where you can talk about what you are doing would be good."

Indeed, much (but not all) of the activity on the Dusted Community site in this pilot phase involved women members. However, this is not to say that men were not supportive of the idea of the community; for example:

[Talking about the potential benefits of the on-line community for another sufferer]
"Not only [would] it get him out of isolation but gets him involved with others in a community group. He is also connecting with other with similar problems."

Although fewer, there were also some affected individuals interviewed for whom the on-line/technology aspect of the Dusted Community was a prohibitive barrier to entry.

"This is only one big problem a lot of people our age have no idea what to do with a computer...With computers I honestly think that no one can teach you."

Formal feedback from members participating in the pilot phase of the Dusted Community has been resoundingly encouraging. For example:

"So far, I think the website is great. I have never been part of anything like this before, I am not even on Facebook, so I don't really have anything to really compare it to, but so far it has been great. I feel, despite the fact that it is only a small group, we are already starting to support/inspire each other. It has been nice getting to know the other members a little bit."

VIA A PROCESS OF INTERACTIVE SUGGESTION, REFLECTION, AND REFINING, OUR BRIEF BECAME TO CREATE A SAFE, ON-LINE VIRTUAL COMMUNITY - NOT ABOUT ASBESTOS-RELATED DISEASES, BUT **FOR THOSE AFFECTED BY SUCH DISEASES**



THE DUSTED COMMUNITY IS A **PEER-TO-PEER SUPPORT GROUP** FOR INDIVIDUALS WITH AN ASBESTOS-RELATED DISEASE AND THEIR FAMILIES. NOT CONSTRAINED BY THE PHYSICAL AND GEOGRAPHICAL DEMANDS OF TRAVELLING TO A SINGLE CENTRE, **MEMBERS CAN LOG IN ANY TIME OF THE DAY OR NIGHT** TO SHARE THEIR STORIES OR TO MAKE CONTACT WITH OTHERS IN SIMILAR SITUATIONS FACING MANY OF THE **SAME CHALLENGES**.

WHERE TO NEXT?

This research has yielded insight into the nature and extent of social and economic challenges facing men and women affected by exposure to asbestos and enhanced our understanding of the psychological impact of an asbestos-related diagnosis, particularly as regards Carers. The Dusted Community has provided the means to begin to explore the potential of online peer support to increase levels of social interaction and reduce isolation.

These findings have many implications for the design of services and support. At the same time the emergence of a younger, third wave cohort of men and women affected by exposure to asbestos in non-occupational settings will create a new set of challenges, not only for those directly affected but for Australian society as a whole. How can these challenges be addressed?

SUPPORTING THE WELL-BEING OF CARERS

Caring for someone with an asbestos-related diagnosis extracts a significant toll on the person who assumes this responsibility. The third wave of exposures has also signalled a change in the typical care profile. Previously predominantly women, often nearing retirement age increasingly, younger women and men, still of working age and not infrequently with family responsibilities are being called upon to undertake this role.

There are very good social and economic reasons to ensure that Carers, current and future, are well and consistently supported in their role. The challenge for government,

organisations and professionals working within this space is how to engage with, and support this community effectively. Support is particularly important at crucial points in the caring journey, including upon diagnosis and after the loss of the person for whom they cared.

A series of integrated initiatives designed to provide Carers and families with tailored information and advice across a range of different areas upon diagnosis would go some way to providing this support. Consideration should also be given to reviewing and simplifying the process of claiming welfare benefits by Carers, both for themselves and on behalf of the person diagnosed. Ideally Carers should also be able to access the services of a specialist “asbestos” advocate within Centrelink. The role of this advocate would be to guide Carers through the system providing advice and support when necessary.

Targeted and flexible support packages based upon the evolving needs of the carer would also be of benefit particularly if this support continued for a specified period post the loss of the person diagnosed.

In addition to targeted support and services, there is a need for initiatives designed to increase levels of social connection within and across the carer community. Consideration should be given to funding carer specific roles, within asbestos support organisations. Support, resources and the opportunity to share experiences, could be provided via a virtual, peer-to-peer community an initiative

that would be of particular value to regional and rural Carers.

RETHINKING A REGIONAL DIAGNOSIS: SKILLS AND TRAINING AND CAPACITY BUILDING

Whilst much of the specialist treatment associated with an asbestos-related diagnosis will remain clustered in large city centres initiatives designed to increase local understanding and knowledge of asbestos-related disease would enhance regional resilience and help build local capacity.

These initiatives should also provide opportunities for collaboration and knowledge sharing and generate region-specific information.

Examples include:

- Specialised training and resources for regional GPs, nurses and palliative care professionals in order to build regional expertise in asbestos-related illness. Resources should include information around the health, psychological, and social impact of asbestos-related disease for people diagnosed, their Carers and families. An innovative education program for GP's and nurses working with mesothelioma patients was recently developed by the Lung Foundation and funded by the Asbestos Innovation Fund.
- Increased collaboration and knowledge sharing with frontline agencies like Lifeline, Beyond Blue and the Men's Shed.

- Professional organisations like the Australian Psychological Society and the Australian Health Practitioner Registration Agency to provide specialised training and resources to their members.

DURING PHASE 1 OF THE DUSTED COMMUNITY, ALMOST ALL MEMBERS' POSTS TOOK THE FORM OF SUPPORTING, INSPIRING, OR INFORMING OTHER MEMBERS. PEOPLE AFFECTED BY ASBESTOS-RELATED DISEASES ARE KEEN TO SUPPORT EACH OTHER.



LOOKING FORWARD: MANAGING THE POTENTIAL IMPACT OF THE THIRD WAVE

Government, at both a federal and state level has a key role to play in managing and mitigating the potential social, economic and psychological impact of the third wave of asbestos exposures. In order for initiatives and interventions to be effective an understanding of how the third wave might unfold in an Australian context is needed. This will involve an analysis of how support and services are currently delivered in each state. The fact that the scope of this research has been largely confined to NSW suggests the need for similar research within other Australian states and territories

The establishment of a national asbestos research fund focussing on the short, medium, and long-term implications of exposure to asbestos including the third wave of exposure to asbestos would build on existing knowledge and enhance our understanding of the potential impact of an asbestos-related diagnosis. A key role of such a fund would also be to encourage and promote innovative and interdisciplinary asbestos research collaborations between researchers 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.

EDUCATION AND AWARENESS RAISING: THERE IS STILL WORK TO BE DONE

Many project participants spoke about the need for more awareness about the continuing dangers of asbestos. Many also spoke of their own experience. The asbestos awareness issue has three dimensions; (i) lack of awareness of asbestos diseases, (ii) lack of awareness about the risks related to asbestos within the community, and (iii) lack of awareness of available social and financial support.

Referring to levels of awareness during the 1960's and 70s, the time when most of the older participants were exposed to asbestos most opined that **...nobody knew much about it.** One participant recalled an incident when someone asked him **...how much does it (asbestos dust) take and I said it only needs one...its lack of education....still thinking it's not going to happen to me.** Although none were absolutely sure, some believed that their employers knew about the asbestos **....but they didn't want to let us know....they only wanted to get the job done.**

A perceived lack of awareness within the broader community today appears to be a major concern. Some were sceptical of the role of media **...it really worries me when you watch those reality programs (showing home renovations) on TV or anything like that. They have to do something about that....** One of the Carers was shocked when she heard a senior member of the hospital staff **... laughing and joking** (about some renovations he was doing himself) **...as he said I've always been careful but this lot I'm just going to put in the recycle binI said why don't you give your kids a gun ...**

Finally, there were comments indicating a lack of awareness of the available support for people with an asbestos-related diagnosis. Many participants commented on the need for more information and support, particularly for people living outside Sydney... Some suggested that (online support groups) **would help them** (people outside Sydney) **it's important for people who don't know a damn thing about it.** Others spoke of the need for more opportunities to connect with peers... **I mean people like myself getting together, educating themselves and sharing information.**

APPENDICES

RESEARCH METHODS

1. SOCIAL AND ECONOMIC IMPACT: THE QUALITATIVE RESEARCH

The research team spoke to a total of 26 people affected by an asbestos-related disease during the course of this research. The interviews took the form of a semi-structured conversation designed to explore the social and economic impact of an asbestos-related diagnosis on the lives of each interviewee. Interviewees were identified in consultation with ADFA and via the project questionnaires.

The interviewees comprised men and women with an asbestos-related diagnosis and Carers, both current and past. One interviewee had been extensively exposed to asbestos but had not been diagnosed. Another interviewee had not been exposed personally however three members of his immediate family had been exposed and diagnosed.

A preliminary and manual analysis of the data generated by the first ten interviews by the research team revealed a number of emerging themes. The themes were reviewed and refined at the conclusion of the interview process. The research team discussed two methods of data analysis, computer assisted and manual. The use of a computer assisted qualitative research analysis tool like, for example, Nvivo was

SYDNEY	NEWCASTLE	REGIONAL NSW	TWEED HEADS	TOTAL NO. OF INTERVIEWEES
8	2	15	1	26

TABLE 1 PARTICIPANTS BY REGION

DIAGNOSED WITH MESOTHELIOMA	DIAGNOSED WITH ASBESTOSIS	DIAGNOSED WITH PLURAL PLAQUES	CURRENT CARER	PAST CARER	EXPOSED BUT NOT DIAGNOSED/OTHER FAMILY MEMBERS DIAGNOSED
7	1	6	6	4	2

TABLE 2 PARTICIPANTS (MEN AND WOMEN) STATUS

DIAGNOSED WITH MESOTHELIOMA	DIAGNOSED WITH ASBESTOSIS	DIAGNOSED WITH PLURAL PLAQUES	CURRENT CARER	PAST CARER	TOTAL NO. OF WOMEN INTERVIEWED
1	1	1	6	4	13

TABLE 3 WOMEN PARTICIPANTS

considered as was a manual analysis combining both a literal and interpretative approach to the data.

Whilst the volume of data generated (in excess of 200 pages of transcript) suggested a computer assisted analysis the decision was taken to analyse the data manually. Of particular relevance was the fact that respondents expressed similar ideas and concepts in completely different ways thereby increasing the risk of a partial data retrieval using a computer assisted analysis. For example when talking about the social impact of a diagnosis, respondents expressed the loss of social mobility using a range of different concepts. One carer highlighted her husband's inability to engage in simple everyday forms of recreation.

"Like [B] would have loved to have gone on his bike and gone for a ride, or just gone for a walk down to the beach. But he couldn't do it, like, so you have nothing. That is all your life is."

Another interviewee spoke of the retirement he had planned but lost:

"That was what I was going to do in my retirement join the local bowling club. I was doing that for about one year. I didn't retire until I was 68. That was my plan cause [sic] I was pretty good at it. I was going to become a fulltime member & travel around & play against other clubs. But this thing came up & threw it all away."

A computer generated search based on individual words within each response would not have identified similar responses because of the different ways in which the idea of loss had been expressed.

Having made this decision the emerging themes previously identified were organised into an analysis template and the interviews coded accordingly. In order to ensure consistency of interpretation within the team the first 10 interviews were coded independently by two researchers

and the results compared. After confirming a consistent approach the remaining interviews were coded by one of three researchers.

An analysis of the coded data has now been undertaken. This analysis has informed our understanding of the social and economic impact of asbestos-related disease, together with the attendant disadvantage, across and within a number of different communities. A series of further analyses both within and across the various themes will enhance this knowledge and will form the basis of future academic articles as well as briefings to project stakeholders.

IN PHASE 1 OF THE DUSTED COMMUNITY, FEMALE MEMBERS WERE MORE ACTIVE ON THE SITE THAN MALE MEMBERS. MORE NEEDS TO BE DONE TO FIND OUT WHAT SPECIFICALLY ENGAGES MEN IN AN ON-LINE SUPPORT COMMUNITY.

**"THIS MESOTHELIOMA, NOBODY SEEMS TO KNOW ANYTHING ABOUT IT. SO ANYTHING TO GET IT GOING, I'M HAPPY TO HELP IN ANY WAY."
- DUSTED COMMUNITY MEMBER**

2. PSYCHOLOGICAL IMPACT: THE QUANTITATIVE RESEARCH

Quantitative data was collected using a survey instrument consisting of questions relating to demographic variables such as age and gender, disease status, etc., and the following instruments:

- The Assessment of Quality of Life instrument (AQoL) (Hawthorn, Richardson & Day, 200)
- Six items selected from the MOS 36-item Short Form Health Survey (SF36) (Ware & Sherbourne, 1992)
- The Multidimensional Scale of Perceived Social Support (Zimet, Dahlem, Zimet & Farley, 1988)
- The Connor-Davidson Resilience Scale (Connor & Davidson, 2003)
- The 21 item Depression Anxiety and Stress Scale (DAS21) (Lovibond & Lovibond, 1995)

The survey had two main purposes: Firstly, it provided information about the nature and level of psychological distress experienced by those with a diagnosis, Carers and family; and, secondly, it provided a means by which individuals could be contacted in order to seek their participation in interviews and in the Dusted Community..

Participants comprised 32 individuals with a diagnosed asbestos-related medical condition, and 15 Carers or family members. Of those with a diagnosed medical condition, 33% had been diagnosed within the last 5 years, but 30% had been diagnosed between 1980 and 2000. The earliest diagnosis of mesothelioma was in 2001. There were 28 males and four females with a diagnosed condition, and three male and 11 female Carers and family (one individual's data missing).

PROCEDURE

The survey was distributed on a number of occasions, and some changes were made to portions of the survey following feedback from stakeholders.

The first version of the survey was distributed as a hard-copy insert to a Mail-out of the ADFA Newsletter. A reply-paid envelope addressed to the research team was included in this mail-out. This version of the survey included the AQoL and was designed to be completed only by individuals who had been diagnosed with an asbestos-related medical condition.

Following feedback from recipients and other stakeholders, a new survey

instrument was designed that was appropriate for both those with a diagnosed condition, and those without (Carers and family). For respondents who identified themselves as having a diagnosed condition the number of AQoL items was reduced to eight, modified to be rated on a Likert scale, and the SF36 items were removed entirely. The survey was mounted on Survey Monkey, and participants were sought through communications providing the link to the Survey Monkey on mail-outs from ADFA, Slater & Gordon, and AsbestosWise. A further distribution of the hard-copy version of this instrument was made to individuals on the Slater & Gordon mailing list.

3. THE DUSTED COMMUNITY

Given the large numbers of Australians diagnosed with an asbestos-related disease, the fact that many of these are in suburban, regional, and remote areas of the country, and that a third wave of such diseases is virtually upon us, an on-line platform for such a peer-to-peer community seems to be an ideal fit. By adapting effective strategies from related areas, we worked to establish an on-line peer-to-peer support group—a ‘virtual community’—for individuals with an asbestos-related diagnosis and their families.

The research team consulted with potential members to come up with the name for the community, which became ‘the Dusted Community’ (<http://dustedcommunity.net>). ‘Dusted’ is a term used in Australia to refer to someone exhibiting physical symptoms resulting from exposure to asbestos fibres (e.g., “I knew I was dusted as soon as I saw the doctor’s face”).

Consultation with members of ADFA and with other affected individuals, using the principles of participatory action research took place over a number of months in order to identify needs and priorities. Through this process of interactive suggestion, reflection, and refining, the brief became to create an, on-line virtual

community that was not so much about asbestos-related diseases, but for those affected by such diseases. So, from the original conception of a community comprising fact-sheets and links to hard information on the medical and legal aspects relevant to asbestos-related diseases, the eventual plan, driven by the project’s stakeholders, became to develop a friendly, supportive on-line environment where members could interact with each other, share their stories, and listen to the stories of others. The idea of a separate area for Carers became a key priority, enabling Carers to join the main members’ space as well as break off into their own virtual room.

The site was established over several months on the v-team (vteam.com.au) web server and was opened to its first intake—of ‘friendly testers’—in August, 2013. Discussion and interaction was encouraged by the community facilitator. In October 2013 members were asked to provide feedback and suggestions after their initial period of membership. This feedback was overwhelmingly supportive of the project continuing.

“... TALKING TO PEOPLE THAT HAVE GONE THROUGH IT IS EASIER THAN TALKING TO OTHER PEOPLE”.
- CARER

NEW KNOWLEDGE

DUSTED COMMUNITY:

PILOTING A VIRTUAL PEER-TO-PEER SUPPORT COMMUNITY FOR PEOPLE WITH AN ASBESTOS-RELATED DIAGNOSIS AND THEIR FAMILIES

Accepted by the: Journal of Psychosocial Oncology 10-Feb-2014

Authors: Desiree Kozlowski, Stephen Provost, Julie Tucker, Rick van der Zwan

Abstract

Individuals with an asbestos-related diagnosis and their Carers face burdens including debilitating and life-limiting physical symptoms and medico-legal stressors. Feelings of social isolation are common. Increasing social connectedness can lead to increased feelings of personal empowerment and may inhibit chronic stress responses. We report on the development, via a process of participatory action research, of an on-line peer-to-peer support group, and the first 30-day test phase of this virtual community. Initial indications are that individuals with an asbestos-related diagnosis and their Carers can benefit, in psychosocial terms, from membership of an on-line support group comprised of experientially similar others.

Keywords: asbestos; mesothelioma; support group; social connectedness; psychosocial support

PSYCHOLOGICAL IMPACT OF ASBESTOS DISEASE: A SYSTEMATIC REVIEW

Submitted March 2014 to: PLoS One

Authors: Stephen Provost, Desiree Kozlowski, Jacalyn Hall, Julie Tucker, and Rick van der Zwan

Abstract

This systematic review was conducted under the PRISMA protocol in order to establish the extent and nature of evidence for the psychological consequences of asbestos exposure. The review identified a limited number of publications (11) relevant to this question. The qualitative synthesis of these papers revealed a number of discrepancies between the outcomes of studies making it difficult to draw any general conclusion in either direction. No study employed a fully randomised participant selection procedure. A large number of different instruments have been employed for the evaluation of psychological distress, further increasing the difficulty with which direct comparisons between studies can be made. Research into these risks will benefit from the establishment of agreed standards for data collection to enhance comparability of results across studies and geographic borders. Many of the studies in the qualitative synthesis have been published since 2010, suggesting a welcome increase in interest in the psychological risks associated with asbestos exposure. It is critical that the relation between asbestos exposure and psychological distress be understood in order to provide the evidence base needed for the provision of appropriately-targeted support for individuals in this area of growing need.

Keywords: Asbestos, Psychological distress, Systematic review

THE ASBESTOS EPIDEMIC:

A REVIEW OF ECONOMIC AND SOCIAL IMPACT

Authors: Suman Sen, Jeremy Buultjens, Grant Cairncross, Julie Tucker

Abstract

Asbestos-related diseases have significant physical, emotional, social and economic impacts on people diagnosed with an asbestos related disease, Carers, and their families and friends. Lack of research into the social and economic impacts, particularly in an Australian context, is likely to impede effective management of the asbestos epidemic in this country. The task appears to become even more daunting as both men and women, across all age groups, will be equally vulnerable to the emerging third-wave of asbestos exposure.

Given the paucity of knowledge in this area, the review commenced by looking into the impacts of occupational injury and illnesses and cancer, and then delves into the impacts of asbestos diseases. The rationale behind inclusion of the former two is that a significant number of asbestos patients contract this disease for occupational reasons, and cancer being a terminal illness, provide an insight into the challenges faced by asbestos patients, their family members and Carers. All relevant economic and social impacts, and their respective moderators i.e. factors influencing the extent of impacts have been extrapolated.

A number of gaps also emerged from the literature which warrants further investigation. Firstly, economic impacts of asbestos-related diseases on patients and family members need to be better understood as third wave victims may not be able to claim workers compensation. Secondly, most studies focus on mesothelioma and do not shed much light on the impacts of non-malignant non-occupational cases despite the fact that different asbestos diseases affect patient's health in different ways, require different treatment plans, and level of care. Thirdly, social impacts on Carers remain largely unexplored. Although some researchers reported on this aspect, all limited their focus on mesothelioma and/or lung cancer. Fourthly, the literature is very much focused on aged and retired workers who are likely to experience challenges different from those confronted by patients from different demographic (age, sex, language, ethnicity, etc.) profiles. Fifthly, the literature frequently refers to specialist medical services required, but does not specifically explore the economic costs involved for those who live in regional areas and travel to urban centres for treatment. Finally, lack of research in an Australian context is a serious limitation given that Australia was one of the highest users of asbestos in the 1950s. Findings from other studies cannot be generalised either because public health systems, social security benefits, workers-compensation processes and support from external sources usually vary between countries.

Keywords: Asbestos, Social Impact, Economic Impact

