

Plenary Presentation

5.6 SUPPORT AND COUNSELLING OF ASBESTOS DISEASE VICTIMS AND THEIR FAMILIES

and

CASE STUDY – A WITTENOOM FAMILY

(Ed. Some of the pictures in these presentations exhibit sharpest definitions at around 260% magnification, though one requires 350% and another group are best at around 200%.)

Support and Counselling of Asbestos Disease Victims and Their Families

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Osasco Brazil September 2000

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Asbestos Diseases Society of Australia Summary of 1999 Calendar Year

1. Correspondence: Incoming plus facsimile 41,710 and outgoing plus facsimile 53,242.
2. New Clients: 547 new registers regarding investigations of possible asbestos-related disease.
3. Diagnosis of asbestos-caused disability: Pneumoconiosis 72, lung cancer 36, mesothelioma 101 and asbestos pleural disease 237.
4. 74 clients/members were assisted with Pneumoconiosis Medical Panel examination in accordance with Section 36 of the Workers' Compensation and Assistance Act 1981 (most of the applicants received a determination of disablement from industrial diseases). More than 30 members residing Interstate were assisted with compensation/damages claims and a further 72 were provided with information on medical matters associated with asbestos caused diseases..
5. Deaths: Sadly more than 130 of our dear friends and members have lost their lives due to asbestos-caused diseases.
6. Approximately 28,000 general inquiries were received by the ADS office re: medico/legal matters, Social Security, Workers Compensation, Comcare, Veterans Affairs entitlement, taxation matters and other confidential issues.
7. Approximately 1000 general environmental asbestos inquiries were received from the community and both private and public instrumentalities (ADS Environmental Officer assisted by ADS Advisory staff , attended to most of the enquiries.
8. 2-3 visits per week were carried out by ADS caring counsellors to sick members both at home and in hospital, including visits outside the metropolitan area.
9. Members and Friends Picnic at Dizzy Lamb Park and a number of mesothelioma/lung cancer support group meetings were held.
10. A portion of fundraising proceeds was allocated for the research into asbestos caused diseases.
11. Seminars on asbestos risk and its consequences were arranged in both city and country areas.
12. The Ecumenical Memorial Service was held at St George's Cathedral
13. More than 2000 free lung function tests were carried out as a part of the Asbestos Diseases Awareness Programme and service to the Western Australian Community.
14. ADS office successfully resolved 41 Workers' compensation claims by negotiation or through the Conciliation and Review process. Also assistance was provided to 87 members who pursued damages claims at Common Law and including product liability claims.
15. Attendance to International, Interstate and Local Conferences relating to asbestos diseases medical research, legal matters and other related issues.

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Introduction

The Blue Asbestos mine at Wittenoom Gorge has left Western Australia with the dubious distinction of having the highest per capita incidence of mesothelioma in the world.

The Blue Asbestos mine at Wittenoom Gorge may be viewed now and in history as the site of Australia's greatest industrial disaster.

The Wittenoom mine was closed more than 30 years ago, but the legacy remains.

It has left thousands dead, dying or likely to die of asbestos related disease.

The Wittenoom mine has also left Western Australia with the dubious distinction of



Wittenoom Blue Asbestos Mine and Mill

having the highest per capita incident of mesothelioma in the world.

Yet the nightmare does not end there. It was not just the Wittenoom mine, mill and transport workers who were subjected to horrific exposure to asbestos fibres. Despite warnings from authorities, asbestos tailings were used to line the streets of Wittenoom and even the playgrounds of the local school.

As a result, it is not just the workers from Wittenoom who are dying at appalling rates. It is their spouses and their children, who innocently played in the strange blue dust. It is the tourists who stayed in Wittenoom while they explored the rugged and spectacular ochre-tinted mountain ranges and gorges of the area. It is the woman who spent just three weeks at the Wittenoom caravan park, waiting until accommodation could be found for her family at nearby Roebourne.

It is the police officers, the teachers, the nurses, the postal workers and their families, sent to Wittenoom to do their duty.

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Then there are the victims who have never been to Wittenoom. Thousands of tradesmen and others came into contact with the “wonder fibre” at their workplace. Waterside workers lugged bags of asbestos on the docks. Asbestos-cement factory workers, carpenters and tradesmen used asbestos in building products day in and day out. Railway workers installed insulation on trains. Navy personnel were exposed to asbestos in the engine rooms of war ships.

Western Australia is one tragic scene on the world stage. Diseases caused by exposure to asbestos claim many lives and affect many families around the world every day of the year.

In spite of the astounding technology and the medical knowledge accumulated this loss of life still continues.

My comments for this paper are drawn from my personal and work experience. Firstly, that my husband was a former Wittenoom Blue Asbestos miner and secondly as a master builder my father took me as his assistant to his weekend building projects which involved mostly work with asbestos sheeting, finally from my work at the Asbestos Diseases Society of Australia Inc (ADSA) and the Asbestos Diseases Advisory Services (ADAS) over the past 21 years, assisting asbestos disease victims and their families.

Wittenoom unleashed an asbestos caused medical, social and legal crisis in Western Australia. It was the unfolding of this tragedy that led to the formation of the Asbestos Diseases Society of Australia Inc and its Advisory Service.

Legislation needed to be changed and a structure created to assist people at risk of and affected by asbestos related diseases. The 30 to 50 years needed to develop asbestos disease made it necessary to design a system that monitored and supported the still unaffected as well as those already diagnosed.

The ADSA started with a small cardboard box and a borrowed typewriter. Today, the ADSA has a large, efficient, multi-purpose premises, with 7,500 members and their families to care for.

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A Day in the Life of the Asbestos Diseases Society and Its Advisory Service

On any one day, the work carried out is incredibly diverse. A member with mesothelioma, who lives in government housing, rings the office wanting help to find new lodgings. (His current apartment is on the fourth floor and he is too breathless to climb that many flights of stairs.)

A community member who is also a tenant in government housing rings to report loose asbestos fibres in the ceiling and wants the ADAS to intervene with the authorities. Another caller has been refused a disability pension from the Government because he can't explain that he has mesothelioma and is seeking a resolution to his social security problems.

Compensation hearings need to be attended. Hospital and home visits need to be fitted in to this busy day. The ten telephone lines, fax and email never stop. Endless paperwork is slotted between personal contacts – work histories, legal statements, arranging and attending medical appointments with members, preparation and paperwork for the Pneumoconiosis Medical Panel (part of the compensation process). On some days there will be a support group meeting or a group of members preparing for society activities or the thousands of newsletters for posting.



Asbestos Diseases Society Office Today

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The New Member

A new member will first make contact with our Society when they have a known asbestos exposure which is concerning them or when they have been diagnosed with an asbestos disease.

There are four recognised asbestos injuries and these are each distinctly different.

Pleural Plaques – which are benign patches of thickening, which may appear on the lining of the chest wall and over the diaphragm in the pleural membrane that lines the chest.

Asbestosis – a benign process in which the lung becomes stiff and less elastic, so that shortness of breath occurs.

Lung cancer – is a malignant tumour of the airways or lungs. Research has shown that asbestos workers who smoke are 8 times more likely to develop lung cancer.

Mesothelioma – is a malignant cancer of the outer covering of the lung, called the pleura. Less commonly it can also occur on the peritoneum and occasionally on the pericardium.



Nine young men leaving Rome in the mid 50's to work at Wittenoom Blue Asbestos Mine. (Eight have died from asbestos diseases)

Explaining the differences between these disease processes to a sufferer is very important particularly when a sufferer has difficulty understanding and accepting the diagnosis. Misunderstanding of the diagnosis can lead to unnecessary anxiety and hardship. For example: a person came into the ADSA office and stated he had been diagnosed with pleural plaques. He had bought a coffin and held his wake believing this to be a fatal condition. If necessary a second opinion is facilitated to clarify diagnosis.

Another person rushed into the ADSA office to say how relieved he was that he didn't have that terrible asbestosis, he only had mesothelioma.

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Receiving a Diagnosis

Today the medical fraternity has greater awareness, understanding and knowledge about asbestos diseases and a diagnosis is usually made quickly.

For the sufferer diagnostic processes can be intimidating, invasive and painful. In some cases a definite diagnosis may still not be achieved. In such a situation a plan for observation by periodic x-ray and CT scanning is usually set in place. If clinical observation shows progression of disease, a biopsy may be taken.

Observation generally occurs at intervals of three months. After six or nine months a diagnosis may still be inconclusive although the patient is visibly deteriorating, sick and in pain. While it seems obvious that something terrible is going on, there is no confirmation and the patient is caught in a limbo:



May Day festivities at Wittenoom 1953, The May Queen and six other children in this group have passed away with mesothelioma.

unable to plan for the future, nor able to decide to finalise his/her affairs.

The longer it takes a person to be properly diagnosed, the more psychologically disturbed they become, particularly when they are finally diagnosed and they are told they may have only months to live.

The degree of distress this causes is indicated by the comments of one man: he was relieved to finally be told he

had mesothelioma because it indicated that his decline was not a "madness in his head" and he could at last take some sort of action.

Honesty and openness, tempered with sensitivity, between the doctor and a patient make the process more manageable.

Pain Management

Pain management is essential. Successful management of pain requires assessment of all aspects of a patients suffering and treatment must be part of a co-ordinated plan of total care. Pain is subjective. Pain is best managed by early intervention. The treatment of cancer related pain is not easy and requires communication and perseverance. The Specialist will consider pain management in conjunction with maintenance of maximum function.

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Delivering the Diagnosis

Time constraints may prevent doctors from meeting the needs of someone who has been told that they have mesothelioma. Each individual absorbs and accepts the information according to their own philosophies and coping mechanisms, or lack of them. It takes time to grasp the enormity of the information and its effect on their life circumstances.

The ADAS has tailored services to provide help at this sensitive time. Families are counselled and can take as much time as they need in any number of visits.

Both the diagnosis and the prognosis need to be explained thoroughly without delineating time frames. This is done step by step as each person wants the information. Providing options for the management of symptoms will also lessen anxiety and fear. Educating diagnosed individuals about their situation and encouraging them to take an informed and active role in decision-making builds a sense of security and control. This reduces feelings of helplessness and anger and also aids in the setting of realistic and attainable goals that are acceptable within the new terms of the person's life.

Assisting in such a reorientation is never easy. Individuals diagnosed with an asbestos injury often isolate themselves. At the ADAS initial and subsequent contacts assist in overcoming this self-imposed exile.

Asbestos diseases are socially disruptive and financially destructive.

Medical Research

The researchers at Sir Charles Gairdner Hospital, Perth, Western Australia have for a number of years given mesothelioma patients a reasonable chance to extend their predicted life expectancy by participating in mesothelioma treatment trials.



Asbestos Diseases Research Information – Displayed at ADAS Premises

To date the research has increased the general understanding of asbestos diseases and has resulted in new treatment approaches to mesothelioma, resulting in the partial or total shrinkage of tumours in a number of patients. Although not all on the treatment trials have responded, many patients have benefited by extended quality of life.

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Counselling the ADSA Member and their Family

A large amount of time is spent with the loved ones of members who have been diagnosed with mesothelioma or lung cancer. Talking with the family, in a relaxed atmosphere assists in guiding them through the uncertainty of the future that they and their diagnosed loved one face dealing with the reality of a fatal disease.



Two young boys play in blue asbestos tailings at Wittenoom, in the mid 1950's both have since died of Mesothelioma aged 34 and 37.

The benefits of a healthy diet, adequate rest and family support are discussed. A close relationship with the supervising general practitioner is encouraged, as is the need for early intervention when changes occur in symptoms.

It is a delicate balancing act between giving hope for the future and preparation towards the time of death.

Special Needs of Families Living with Mesothelioma/Lung Cancer

When a family member is diagnosed with an asbestos cancer a group of special needs is created for the family and the diagnosed person.

These are divided into three groups

- PSYCHOLOGICAL
- SOCIAL
- LEGAL

Although each need will fall into one of the three groups, they are interactive.

Each person or family will react individually and their needs will occur in different orders and combinations and at different times. ADAS provides emotional support, working closely with each individual or family and listening to the issues that they face.

Being understanding and sensitive will make it possible to offer individuals or families the appropriate help for their current need and a practical plan for future support. Exploring suggestions of ways in which family members can assist their loved one provides a sense of purpose and direction.

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Psychological

The psychological stress on an individual diagnosed with mesothelioma can be huge. This is compounded by the knowledge that the sufferer's life has been shortened.

Other factors that add to stress are the problems of settling compensation. The added worry about coping with costs from day to day and how a diagnosed individual's family will cope financially after they have gone.

There have been instances over the years of people with asbestos injuries cracking under the pressure. Case histories are littered with personal tragedies such as suicide, divorce and nervous breakdowns.

Diagnosed individuals are counselled and encouraged to talk to other people in similar situations.

Through the support of the ADAS mesothelioma and lung cancer support group meetings members discover they are not alone, that the problems they have are not unique. Psychological well-being is possible by increasing understanding, introduction to support systems and choices.



Mesothelioma Support Group Meeting at the ADSA Building

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Social

Feeling ill, breathlessness, pain and frustration are major problems for persons with asbestos injuries. No longer being able to work in a job or at home or take part in even low-key pastimes such as walking or golf.

The progressive nature of asbestos injuries also works against any meaningful form of rehabilitation.

The ADAS provides knowledge of the support services that are available from the ADAS office and in the wider community such as housing, disability support, legal wills, Workers' Compensation and Common Law claims.

The social security system provided by the Australian Government isn't always adequate or sympathetic and in special circumstances the ADSA advances money for basics such as food, clothing and transport to hospital appointments.

These are crucial areas in which a person with an asbestos injury generally seeks counselling. Professional guidance aids them in undergoing the painful process of reorientating their lives.

In addition to mesothelioma and lung cancer support group meetings, the ADSA holds family picnics, Christmas parties and an annual Ecumenical Service.

Families of members are invited to become involved in ADSA's activities by helping in the office, folding and sorting, assisting with preparations for the different social functions or making home or hospital visits.



Even grown ups love Santa – ADSA Christmas Picnic.

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Spiritual Concerns

Every human being, whether religious or not, has their own unique spirituality. Spirituality encompasses the purpose and meaning of an individual's existence. Problems related to spiritual concerns occur frequently in patients with cancer, especially advanced disease. Problems may relate to the meaning or value of their life, regrets or guilt about matters past, feelings of anger or injustice, and questions about suffering or the mysteries of death.

Patients who observe particular religious practices may have spiritual problems relating to their religion. People who have let their religious practices lapse may wish to reaffirm their beliefs.

It is important to encourage each person to know their own feelings and to do what is right for them.

Dying

The circumstances of one's death involve strong emotions. Given choice, some people feel safer in hospital and their family prefer the assisted care. Others want to be at home, private and with minimal intervention.

Building a close relationship of trust with the family makes it possible for the ADAS to help them with acceptance that death is approaching and to know when to let their loved one go. Also to help them to be aware of the ways that it can be made a close and shared experience.

Saying "goodbye", "I love you" or talking of happy memories can make a difference to the way the family copes after the death.

After a person has passed away family members, especially a spouse, may need continued support in coping and coming to terms with their loss.

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Bereavement & Support

The experience and expression of grief is specific to each individual. Grief is characterised by shock, numbness, feeling vulnerable and disorganised.

The realisation that their loved one is dead, that the relationship they knew is gone is a period of intense grief and separation pain.

As the family progresses through the grief cycle, they need the support of friends and family, people who will listen to them, and provide assistance with post-death events.

Ongoing matters often keep the bereaved in close contact with the ADAS and support and counselling is offered during this time. In other cases counselling may be done by telephone or home visit. Ongoing support can occur by involving the bereaved in the ADSA activities. Members do a wonderful job helping out with picnics and meetings. Some will provide voluntary transport for members attending appointments. The bereaved individuals feel better when they are able to share their experience and knowledge in the support of other members.

Ecumenical Service

An annual service in remembrance for all those who have died from asbestos caused diseases is held by ADSA. The Service is a multi-denominational service and is held in a major house of worship.

This day is dedicated to the memory of all the men and women who have tragically lost their lives to asbestos diseases.

A large number of families and friends attend the service along with prominent community members, members of government and legal representatives. On average the attendance numbers are between 600 – 800 people.

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Support Group Meetings

The ADSA support group meetings are based on self-help. They are open to all members. Invited speaker's present information on research and treatment trials, symptom management, diet, relaxation and other topics.



Members are invited to speak and to share their experiences.

ADSA Volunteers folding newsletters for posting

The social gathering after the formal part of the meeting allows members to approach the speakers and talk about their situations and meet people in similar circumstances.

Picnics

The ADSA have two picnics each year. 1400 members and their families attended the most recent Christmas picnic. A live band and a barbecue meal are provided. During the year member's make craft items and preserves to be sold, raffled or auctioned. This gives many people a sense of purpose and satisfaction.



The major fund raising raffle is also drawn at the Christmas picnic.

Busy ADSA volunteers preparing the picnic lunch.



Santa and his helpers giving presents to children at ADSA Christmas picnic

The relaxed, outdoor atmosphere encourages people to enjoy a laugh and share their experiences. New friends and old get together. Sometimes it is the beginning of a renewed involvement in life for people who are coming to terms with illness or bereavement.

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Annual General Meeting

At the Annual General Meeting the ADSA elects office bearers and awards are made to people who contribute to the care and well being of those diagnosed with an asbestos injury and their families. Funds raised for research programmes are donated to the special programmes being conducted at Sir Charles Gairdner Hospital, ie mesothelioma research and the Vitamin A Programme.



Dr Greg Deleuil and his wife Maris receiving the Eric Saint Memorial Award for outstanding work assisting victims of asbestos disease

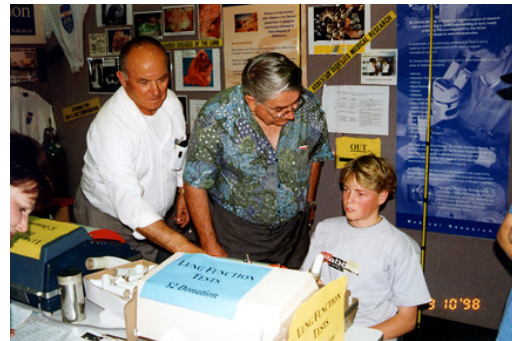
Community Awareness and Education



ADSA volunteers at the information display, Perth Royal Show

The Perth Royal Agricultural Show, the largest annual gathering for residents of Western Australia at which innovations, new products and information services are show cased along with fun rides and children's' activities has been a venue used by the ADSA to raise the awareness of the public for several years.

The ADSA also runs an Asbestos Awareness Week yearly, during which information tables are set-up in the Perth City shopping district offering information on asbestos diseases and asbestos products still in place in the community. Individuals have the opportunity to have a basic lung function test and to talk to a trained ADSA representative. A visit to their general practitioner is recommended if their function is low.



ADSA trained volunteers giving free Lung Function Tests to the public at the Perth Royal Show.

Enormous feedback is received from these open days. A lot of literature is handed out and many questions are answered. Some members of the public go on to have their health checked through the ADSA.

Making people aware of the dangerous condition of aging asbestos products in their homes and workplaces is a major objective of the ADSA.

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Conclusion

The number of mesotheliomas, lung cancers and other asbestos caused diseases has rapidly accelerated over the last decade. Correspondingly the need for the Asbestos Diseases Advisory Services has increased manifold.

Due to the long latency period from the exposure to asbestos fibre and manifestation of asbestos diseases (up to 40 years or more), the epidemic of asbestos diseases is yet to peak in Australia.

It is predicted that by 2020 some 50,000 persons will die from asbestos caused diseases in Australia.

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CASE STUDY – A WITTENOOM FAMILY *By Rose Marie Vojakovic*

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The Person

John, a 33 year old man, married with three children under the age of four, contacted the Asbestos Diseases Society of Australia Inc (ADSA). and its Advisory Service (ADAS) because of his exposure to asbestos at Wittenoom Gorge as a small child.

Through the ADAS he had been medically examined on two occasions over a period of three years and had a clean bill of health.

Then, while coaching junior football John found that he was too breathless to maintain his normal level of activity.



*John as a small child in
Wittenoom*

Diagnosis

Through his general practitioner he had a plain chest x-ray, which showed a large pleural effusion. He was referred directly to his previous respiratory specialist and underwent further tests. At his follow-up appointment with his specialist he was told that he had mesothelioma.

ADSA And ADAS Interaction

John came to the ADAS for information and help with his new situation. One of his main concerns was to financially provide for his young family. He discussed ways in which he could help himself to combat his disease and his legal rights and entitlements.

He was encouraged to consider the option of an experimental treatment trial, which had been suggested by his respiratory specialist.

John commenced a treatment program, which was initially successful in reducing the growth of the mesothelioma. The treatment made him very unwell and he lost a lot of weight. After some months the program was ceased because the tumour had stopped responding.

While John concentrated his time and energy on the treatment program the ADSA and his lawyers were aggressively pursuing his legal entitlement. He was strongly committed to fighting his case in the courts to set a precedent and make an easier legal path for the Wittenoom families who would follow him.

CASE STUDY – A WITTENOOM FAMILY

Court Settlement

John accepted an out of court settlement because his primary need was to provide for his family. He could feel his strength failing too quickly to resolve the matter in court. He felt guilty that he had failed his peers and punished himself for meeting his own needs. During his meetings with the ADAS he was repeatedly assured that this was not so and that he needed his remaining time to be with his family.



John, Dianne and their young family

Faith

John had a strong religious belief and firmly trusted that he would not die. He became bed ridden and his symptoms required hospitalisation for effective management. During the ADAS hospital visits John shared his anxieties. He thought God had deserted him and he was deeply distressed. He felt lost, alone and overwhelmed. He talked about his beliefs, faith and trust. He found a calm acceptance of his position, and decided that what would be would be. John decided to take each day as it came and found that this way he could meet each new challenge and cope better. He had lots of very good days and was able to get special enjoyment from them with his “day by day” approach.

Family Management

John’s wife, Dianne was extremely distressed and had problems coping with their three young children. She felt she was failing John. A family meeting was convened, including John, his parents Barry and Joan, their three daughters and Dianne’s parents. A roster was drawn up, allocating tasks and times to be available to help Dianne. This included time for her to continue her basketball and coaching commitments. These short periods of rest and recreation helped Dianne with her emotional turmoil and improved her patience with the constant needs of the children.

Barry and Joan were very involved and spent every second day at the hospital as John’s condition deteriorated. Dianne spent part of every day with him. Family members would mind the children so that John and Dianne could spend some time alone.

CASE STUDY – A WITTENOOM FAMILY

Barry and Joan felt guilty that they had taken John to Wittenoom as a small child. They blamed themselves for his present situation. They were distraught about their son and fearful for their other children. The ADAS arranged a full medical examination for the family members. All were pronounced fit and well. This helped to ease their minds. Reminding Barry and Joan that there had been no public warnings about Wittenoom or asbestos and therefore they had no knowledge of any danger helped to ease their distress. Being involved in the support and care of John and his family helped his parents and his sisters to deal with their fear and grief.

After John's death in hospital, eleven months from the date of diagnosis, his wife and parents became heavily involved in ADAS activities and the family church commitment remained strong.

The Family After John's Death

Three years later, Barry became extremely ill with an influenza like condition. X-rays and scans showed ominous changes in his chest and a biopsy was performed. The diagnosis from his respiratory specialist was of gross pleural change but no malignancy. He received this news via a mobile telephone call from the other side of Australia. The ADSA approached Barry's respiratory specialist who was present at the same conference to ring Barry with his results rather than have him worrying for another week.

Physically, Barry recovered well but psychologically and emotionally he and the family were shattered. Contact with the ADAS was more frequent in the following period.



Barry and Joan, with their young family in Wittenoom

CASE STUDY – A WITTENOOM FAMILY

Joan's Diagnosis

Six years after John's death, Barry and Joan were on holiday in the north of Australia when Joan became breathless and could not lie down. A visit to a general practitioner was not helpful, so she tried to ignore the problem and cope alone. A subsequent visit to another general practitioner resulted in an immediate flight to Perth. Joan contacted the ADAS before the flight and arrangements were made for her transport and to see the same respiratory specialist who had treated John, as soon as she arrived. Joan was admitted to hospital and diagnostic tests were performed. Waiting for the test results was very traumatic; in spite of her suspicions about her condition Joan was deeply shocked with the diagnosis of mesothelioma.

ADAS Interaction

Many counselling sessions were held with Joan. At the ADAS mesothelioma support group meeting, Joan told those present how important it was that feelings and thoughts be shared so that their families could understand the feelings of grief, anger, fear and pain and be supportive of whatever lay ahead. She spoke of how this had helped her family when her son, John was so ill. Joan explained that good planning and support from her family and the ADAS was the way in which she would combat her disease.

Family Management

Joan's three daughters were experiencing a renewal of their grief for John. They were devastated by their mother's diagnosis and fearful for their own safety. Many telephone calls and visits were made to the ADSA premises during this time of extreme distress.

Joan was not coping well because her pain was not responding to management. Barry had difficulty with this distress and his fear made him think she was not trying hard enough and that things couldn't be that bad.

Joan became filled with guilt, grief and anger that John must have suffered as she was now suffering. She thought she had not done enough for him and that she had not understood. The explanation to her that John's mesothelioma was different from hers and personal to him. That it was controlled well and that he died peacefully, was not helpful or comforting until Joan accepted that her mesothelioma was personal to her. The difficulty that the doctors were having making her comfortable was uniquely her situation.



Barry and Joan (Picture taken one year prior to her death)

Rose Marie Vojakovic, EO, Counsellor, Coordinator of community activities for the Asbestos Diseases Society of Australia Inc & Its Advisory Services. Sept 2000

CASE STUDY – A WITTENOOM FAMILY

Faith

Joan felt that as a Christian it was wrong to be enraged that the company who had employed her husband, had not told them that asbestos was dangerous so she could protect her family. When John was ill she had asked God to take the disease from her son and give it to her. God had allowed her son to die and now was taking her as well. Joan questioned; “Wasn’t one member of her family enough?”

The ADAS helped Joan to understand that her angry reaction was well founded and it was healthy to talk about it. To write a letter to the company stating how she felt would be helpful. She did write the letter. It wasn’t possible to answer the bigger mystery of life and death. Joan felt that if she and Barry prayed together and told God how she felt it would help her to ease her emotional pain and to come to terms with her situation. Joan understood that resolving these feelings would give her more energy for what she needed to do for herself.

Barry dealt with some of his distress by acting on the family plan to sell their family home and move into a small unit so that when Joan came home from hospital he could care for her. He continued to come to the ADAS mesothelioma support group meetings and talked with other men in a similar situation. To have a greater understanding of what Joan was going through he spoke at length with another ADSA member about how she was coping and helping herself since her diagnosis of mesothelioma.

At his next ADAS counselling appointment, Barry cried. He talked about John. He then talked about what he had done and would now like to do for Joan. He explored ways in which he could make her more comfortable at home. Five months after her diagnosis, Joan passed away at home. Her family were all with her.

The Family After Joan’s Death

Barry and the surviving family members are deeply concerned about their health and their future. Therefore regular medical check ups are maintained through their contact and support from ADSA. Anger, anxiety and fear are triggered by flu symptoms, cough or chest pain in any family member.

This family is one of the many families caught in the asbestos tragedy.

The names being used in this case study have been changed for the protection and privacy of the family.