PATIENT INFORMATION

MANAGEMENT OPTIONS FOR

MALIGNANT PLEURAL

MESOTHELIOMA

Jocelyn McLean, RN, MN (Res),
Case Manager for Thoracic Surgery
Eastern Zone, Sydney South Western Area Health Service
Email: Jocelyn.mclean@email.cs.nsw.gov.au
Phone: (02) 9550 1933

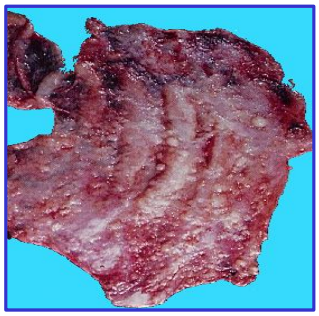
I am but one member of a multidisciplinary surgical and cancer care team. My role is to support patients (and their relatives) through their experience of lung surgery. Patients with mesothelioma often require surgery. Patients who have radical surgery require copious amounts of clinical, physical and emotional support and information.

My contact with patients begins at the time they see one of the five Cardiothoracic Surgeons who work in this group practice. Professor Brian McCaughan has a particular interest and expertise in managing mesothelioma patients and has performed all of the Radical Pleuropneumonectomies mentioned later in this document.

Mesothelioma is a horrible disease and all members of our team endeavor to make the patients nightmare journey a little more tolerable by providing up to date, timely, and appropriate care whilst maintaining a realistic yet hopeful view of the disease and its likely course. Please feel free to ask for more information.

This document is designed to provide an overview of the management options for mesothelioma, from a surgical nurse perspective. I encourage you to visit the websites mentioned at the conclusion for more specific information about asbestos and its affect on the lung, and general lung information.

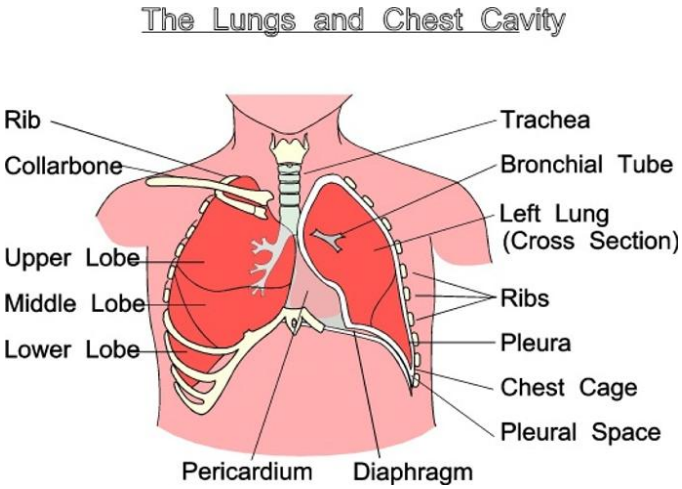
BACKGROUND FACTS IN BRIEF



Malignant pleural mesothelioma is a cancer of the pleura, the thin membrane that covers the lung surface, chest cavity (inside of the ribs), the diaphragm and pericardium (the surface of the heart). There is nearly always a history of exposure to asbestos where fibers have been inhaled some 17 to 40+ years before symptoms of the disease present.

Not every person who has been exposed to asbestos fibres will develop malignant mesothelioma. Many will never have any respiratory signs or symptoms. Some will develop evidence that can be seen only on X rays and CT scans such as pleural plaques. Some may develop symptoms of benign (non cancerous) disease such as chest wall pain.

The most common symptoms of malignant pleural mesothelioma are shortness of breath on exertion and or rest, dull and persistent pleural chest pain, tiredness, weight loss and loss of appetite.



Pleural effusion (fluid collecting in the pleural space) and pleural masses contribute to shortness of breath and pain by reducing the oxygenating capacity of the lung – fluid is heavier than air so it squashes the lung tissue. Draining the fluid (tapping) will enable the lung to re-expand and provide relief from symptoms but this is often only temporary relief as the pleural fluid invariably recurs. Mesothelioma cells are not always diagnosed in aspirated pleural fluid.

A surgical opinion is usually sought for 2 purposes: to control the recurring fluid problem and to obtain tissue for a diagnosis. The surgery is performed via thoracoscopy (keyhole surgery) or thoracotomy (an open operation).

To date, there is no cure for mesothelioma. There is however, a growing interest in this disease such that symptom management is improving, and patients are better able to improve the quality of their life whilst living with the disease.

QUESTION: Why is it important to diagnose mesothelioma?

Mesothelioma is most often a compensatable disease. Malignant pleural mesothelioma is nearly always a result of a person being exposed to and therefore inhaling loose asbestos fibers. The exposure has most often been in a work place but can also be as a result of secondary handling of the dust fibers e.g. washing clothes worn by a person who worked with asbestos. Those people who can identify workplace exposure may be entitled to seek compensation through the Workers Compensation (Dust Diseases) Act 1942-67. All patients are entitled to seek Civil Action through their own legal representatives. Patients and their families stand to gain a significant amount of financial and health related assistance if their claims are successful. A vital factor affecting a claim is the pathological evidence of disease that is obtained more often from pleural tissue (biopsy) and less often from pleural fluid analysis (cytology).

CURRENT TREATMENT OPTIONS for MALIGNANT PLEURAL MESOTHELIOMA:

There are a number of treatment options available to patients diagnosed with mesothelioma. They include:

Medical Oncology (chemotherapy)

Radiation Oncology (radiotherapy)

Palliative care

Surgery

Alternate therapies

MEDICAL ONCOLOGY

There is growing evidence that some chemotherapy agents inhibit (not cure) the activity of malignant pleural mesothelioma. One chemotherapy agent called Alimta (pemetrexed disodium) used in combination with another agent called Cisplatin offers new promise. One randomized control study demonstrated that patients receiving Alimta and Cisplatin increased their survival by 3 months when compared with patients receiving Cisplatin alone. All patients have the right to an opinion from a Medical Oncologist. Our practice is to offer all patients (where appropriate) a consultation with a medical oncologist to discuss the pros, cons, drugs, effects, and possible timing of receiving a course of chemotherapy.

RADIOTHERAPY

Radiotherapy is a treatment whereby a machine directs radiation to a specific site where cancer cells are present. The role of radiotherapy in the treatment of mesothelioma has been limited because it is difficult to deliver optimal doses of radiation to a large area without damaging surrounding tissue and organs. It has been used in small doses to prevent the spread of mesothelioma along the drainage tube tracks that have been used during lung surgery - the success of this use is inconclusive. Radiotherapy has been used in the palliative setting to provide symptomatic relief from disease that has tracked to external tissues, e.g. alone needle biopsy ports, chest tube sites, and for chest pain and other tumor growths related to diffuse pleural disease. There is evidence that radical hemi thorax radiotherapy might benefit patients who have undergone radical pleuropneumonectomy surgery by inhibiting local recurrence of disease.

PALLIATIVE CARE

All patients living with mesothelioma will at some stage require or benefit from support from a Palliative Care Team. Palliative care provides medical and psychological care and support for patients with incurable disease and for those without advanced disease but have symptoms that are difficult to relieve. Early and appropriate referral to a Palliative Care service ensures patients get access to timely expert help with the medical and practical problems of daily life. A vital function of Palliative care is to provide sensitive support to patients and families facing and coping with end of life issues i.e. dying. Each major hospital has a Palliative Care Service. See The Cancer Council pamphlet - Understanding Palliative Care.

SURGICAL MANAGEMENT

Surgery offers effective symptom control, improved quality of life, and hope for an extension of life. A cardiothoracic surgeon who is experienced in managing mesothelioma performs the surgery. The aim of surgery is twofold; to obtain a tissue diagnosis (if not already known) and to treat the most distressing symptom of shortness of breath caused by fluid collecting in the pleural space and impeding expansion of the lung tissue. In general, the type of operation offered depends firstly on the overall health status of the patient and then on the outcome the surgeon expects can be achieved — how much lung re-expansion is likely.

Surgery falls into two categories, palliative surgery and radical surgery.

Palliative surgery is performed via one of two approaches.

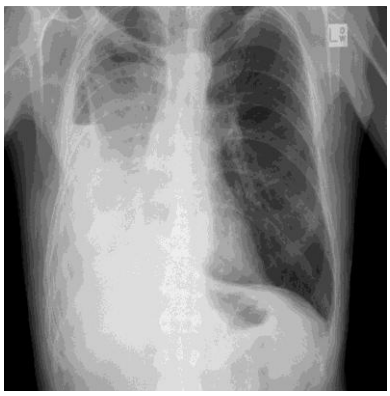
1. Video assisted thoracoscopy (VAT) also known as keyhole surgery or
2. Open via posterior lateral thoracotomy.

Radical Surgery is only performed via posterior lateral thoracotomy.

PALLIATIVE SURGERY

VIDEO ASSISTED THORACOSCOPY and TALC PLEURODESIS

The patient undergoes a general anesthetic. A double lumen breathing tube is inserted so that one lung is continually ventilated while the surgeon operates on the other. Via thoracoscopy the following takes place:



CXR- Right Pleural effusion

A camera is inserted between the ribs into the pleural space via portholes. The pleural fluid is drained and the lung is "freed up" to facilitate maximal expansion.

Pleural tissue samples are taken as biopsies and sent to the pathologist for analysis and diagnosis.

Sterile talc powder is instilled into the pleural space to cause the process of pleurodesis. The powder irritates and inflames both pleura so that the lung lining (visceral pleura) and chest wall lining (parietal pleura) fuse together. This fusion stops fluid production and accumulation.

The lung is re-expanded to its maximum capacity.

One chest drain is left in place sitting between the lung and ribs and attached to a closed chest drain system on low suction. This drain is in place and on suction for a minimum of 48 hours. The suction draws the lung out to force contact between the two pleura. Once the chest drain is removed the patient is free to mobilize and prepare for discharge from hospital.

THORACOSCOPY (KEYHOLE) SURGERY IS BEST FOR:

- Controlling pleural fluid and therefore eliminating repeated painful pleural aspirations (taps).
- Assisting lung re-expansion providing the lung is not trapped down.
- Obtaining tissue for diagnosis.
- Patients' whose lung is easily re-expanded.
- Patients' who would not withstand an open operation.

Unfortunately, thoracoscopic (keyhole) surgery is not always effective if there is a large volume of tumour or the lung has become trapped and not able to be re-expanded – open surgery is therefore required.

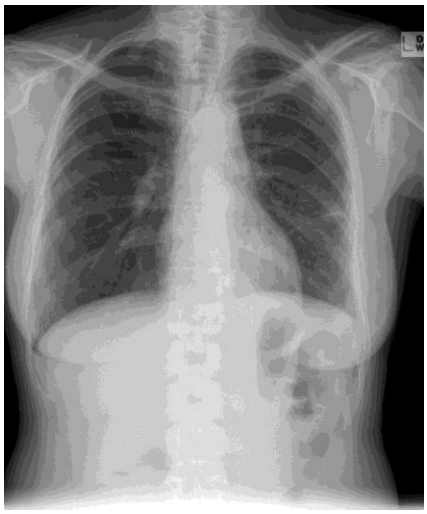
OPEN SURGERY: THORACOTOMY with PARIETAL PLEURECTOMY and PULMONARY DECORTICATION (Palliative surgery)

Following a general anaesthetic and placement of a double lumen breathing tube the chest is opened via the back of the chest and between the ribs (posterior thoracotomy). Several key actions take place:

The pleural fluid is drained and a tissue biopsy taken and all specimens are sent to the pathologist for analysis.

The tumour is debulked by a technique called pleurectomy. The pleura encased with tumour are peeled off the chest wall (parietal pleurectomy) and the lung (visceral pleura). Not all of the pleura is removed – only that which has the worst bulky disease and is safe to remove.

The lung that had been trapped down by the heavy fluid is freed by a technique called decortication whereby fibrous bands are peeled from the lung surface. The lung is re-inflated and re-expanded as much as possible. The inflammatory action of the decortication process causes a pleurodesis.



Two chest drainage tubes are left in place for a minimum of 48 hours as for thoracoscopy.

→ **Expanded lung 6 weeks after thoracotomy.**

THORACOTOMY (OPEN) SURGERY IS BEST FOR

- Controlling fluid and negating painful pleural aspirations.
- Debulking tumour(s)and therefore reducing pleural pain.
- Those who can withstand an open operation and whose lung cannot easily re-expand.
- Assisting lung re-expansion especially when the lung is trapped down.
- Enabling tissue diagnosis.
- Improving quality of life by creating a disease inactive period.

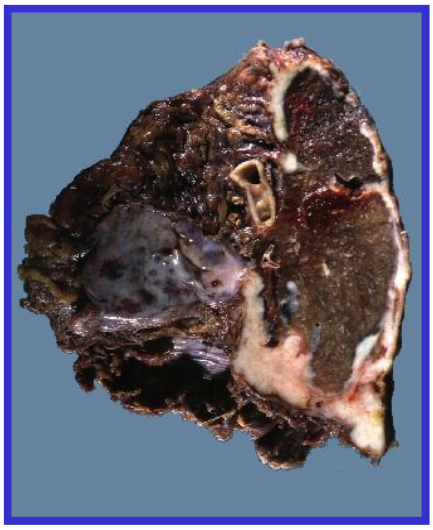
RADICAL SURGERY

Radical surgery is only offered to a very small number of patients with very limited disease and who are deemed fit by the surgeon to withstand the duration, traumas and stressors of the treatment and recovery. The operation is called radical pleuropneumonectomy. In the literature this procedure is also known as (EPP) extra pleural pneumonectomy. The following is a brief synopsis of the surgery.

The chest is opened via an extended posterior lateral thoracotomy (a longer than usual opening on the back).

If a previous keyhole or open operation had been performed, the ribs, skin and tissues surrounding the old drain sites are excised.

The lung, chest wall (parietal pleura), diaphragm (that half on the operation side) and pericardium (lining over the heart) is removed in one piece (en bloc).



The lymph nodes that drain the lung area are removed and sent for pathological analysis.

The diaphragmatic and pericardial defects are reconstructed using a gortex mesh.

The wounds are closed and one chest drain is left in place.

Radical surgery is followed by a 6-week course of radical hemithorax radiotherapy commencing 6-8 weeks after surgery (providing the pathological analysis of all surgical specimens is favorable).
→ Resected specimen in one piece

Radical (right or left) Pleuropneumonectomy with en bloc resection of hemidiaphragm and pericardium, formal mediastinal lymph node dissection, and reconstruction of diaphragm and pericardium with gortex mesh IS ONLY FOR

- Patients' known to have early (limited) disease - most patients would have had prior keyhole surgery for this information to be known.
- Patients with no PET scan evidence of lymph node involvement.
- Patients deemed medically and physically fit enough to withstand the insult of this surgery, live independently with one lung and accept the physical and mental challenges during recovery.
- Patients who wish to proceed after they have had very frank and open discussions with the surgeon and thoracic case manager.

RECOVERY FOLLOWING SURGERY FOR MALIGNANT PLEURAL MESOTHELIOMA

Recovery from surgery is always determined first by the level of fitness and degree of “health” of the patient prior to surgery and then by the type of surgery performed i.e. thoracoscopic or thoracotomy, palliative or radical.

For keyhole surgery the hospital stay is usually 3-6 days. Patients should return to a good level of physical function within 2-3 weeks of the surgery. Further management options should be explored with the primary caring specialist.

Following open surgery the hospital stay is usually 5-7 days. Patients should expect to return to a good level of function within 6-8 weeks of the surgery and be hopeful that they will experience an extended period of quality life while the disease is less active.

Our surgical database has shown that survival following palliative surgical procedures can range from a few weeks or months to many years — up to 11 years in a few cases.

Recovery following radical surgery is much more challenging and for some patients it can be extremely slow following a hospital stay around 10 -14 days. Patients are not expected to return to their “normal” level of activity however in time (and this can be anywhere between 6 -12 months) they should expect to appreciate a satisfying quality of life.

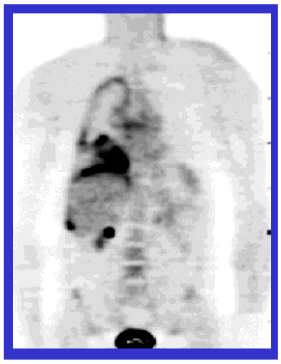
A few patients have not returned home from hospital following radical surgery, some have had complications that have required further temporary hospitalization, but most patients have enjoyed varying periods of “good” quality of life before the disease has relapsed. The longest survivor of 6 years enjoyed many hours of golf and travel following surgery prior to disease recurrence. Many have enjoyed both National and International travel and one patient managed some strenuous walking in Tasmania and did a 4 day assisted walk along The Milford Track in New Zealand.

FUTURE CONSIDERATIONS FOR THE MANAGMENT OF MALIGNANT PLEURAL MESOTHELIOMA

ONCOLOGY

There is ongoing research into the effectiveness of chemotherapy drugs. The chemotherapy agent Alimta (pemetrexed disodium) when used in combination with Cisplatin offers new promise. One randomized control study demonstrated that patients receiving Alimta and Cisplatin increased their survival by 3 months over patients receiving Cisplatin alone.

POSITRON EMISSION TOMOGRAPHY IMAGING - PET scan



The role of PET imaging has yet to be determined in diagnosing and evaluating benign, malignant and metastatic pleural disease. However, PET imaging has demonstrated FDG uptake in some patients with malignant mesothelioma and remains to be further investigated.
(Jadvar, H and Fischman, A 1999. PET Imaging in Pleural Mesothelioma; Joint Program in Nuclear Medicine).

NEW BLOOD TEST

A team of researchers at the Pacific Northwest Research Institute, Seattle, USA and a team from Perth, Western Australia led by Dr Robinson published in the November 15, 2003 issue of the Lancet a report of a blood test that could potentially detect early signs of mesothelioma. Mesothelioma cells are said to release a molecular marker called soluble mesothelin-related proteins (SMR) and it is this marker that is currently under testing and investigation.

'*According to Robinson, from whose patients in Australia the blood samples were drawn, the new research also shows that SMR can be elevated in serum up to several years before actual diagnosis of mesothelioma. "The test may thus prove helpful," Robinson says, "for screening asbestos-exposed individuals for early evidence of mesothelioma"'.*

First- ever Blood Test for Mesothelioma Being Developed
http://www.mesotheliomaweb.org/bloodtest.htm

WHAT CAN WE EXPECT or hope for IN THE FUTURE?

We may see an earlier diagnosis through blood testing.

The PET scan may help in identifying patients with localized disease.

There may be an improvement in overall survival and quality of life by using a combination of therapies such as → chemotherapy, → radical surgery, → hemi thorax radiation therapy

Combined chemotherapy, surgery and radiation might affect a CURE.

SUCCESSFUL MANAGEMENT OF MESOTHELIOMA BY THORACIC SURGERY IS DEPENDENT ON:

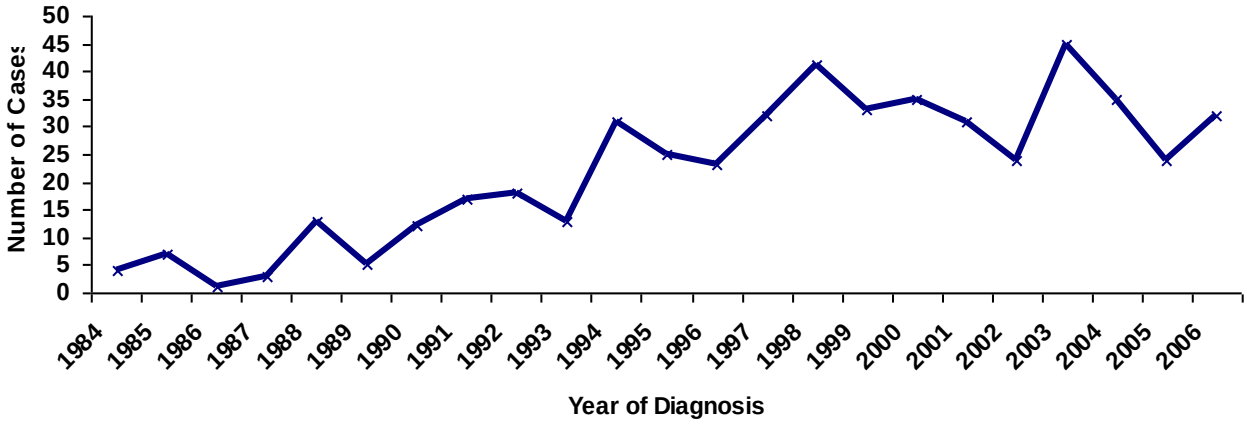
- Deciding what operation best suits the patients' clinical situation and then doing the right operation the first time.
- Providing effective pain relief both in hospital and at home.
- Ensuring effective physiotherapy in hospital and after discharge.
- Ensuring patients have an early referral to centers experienced in managing mesothelioma.
- OFFERING REALISTIC HOPE, BELIEF AND ENCOURAGEMENT.

ASBESTOS RELATED DISEASE IN AUSTRALIA – PREDICTED NUMBERS 1987 – 2020

Asbestosis	1,000
Mesothelioma	13,000 (8,000 - 20,000)
Bronchial carcinoma	40,000 (30,400 - 76,000) (partial attribution with smoking)

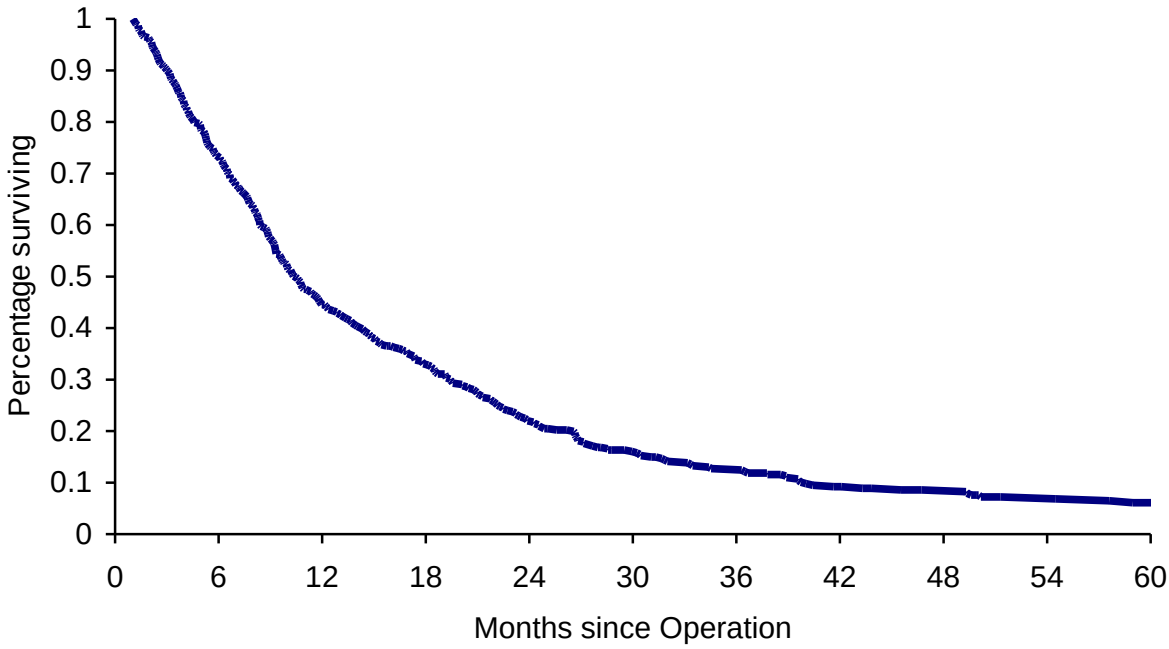
THE EXPERIENCE OF THIS CARDIOTHORACIC SERVICE

505 mesothelioma patients
Average age 66 yrs (22-93 yrs)
427 Males, 78 females (ratio 5.47:1)



Number of patients per year who had surgery with biopsy proven malignant mesothelioma

MESOTHELIOMA - OVERALL SURVIVAL (all cases)



OPERATION BREAKDOWN

Thoracoscopic procedures or keyhole surgery Includes biopsies and pleurodesis	**169**
Thoracotomy procedures or open surgery Includes pleurectomy, decortication, pleurodesis and biopsy	**252**
Radical Pleuropneumonectomy	**62**
Other/Combination procedures	**12**

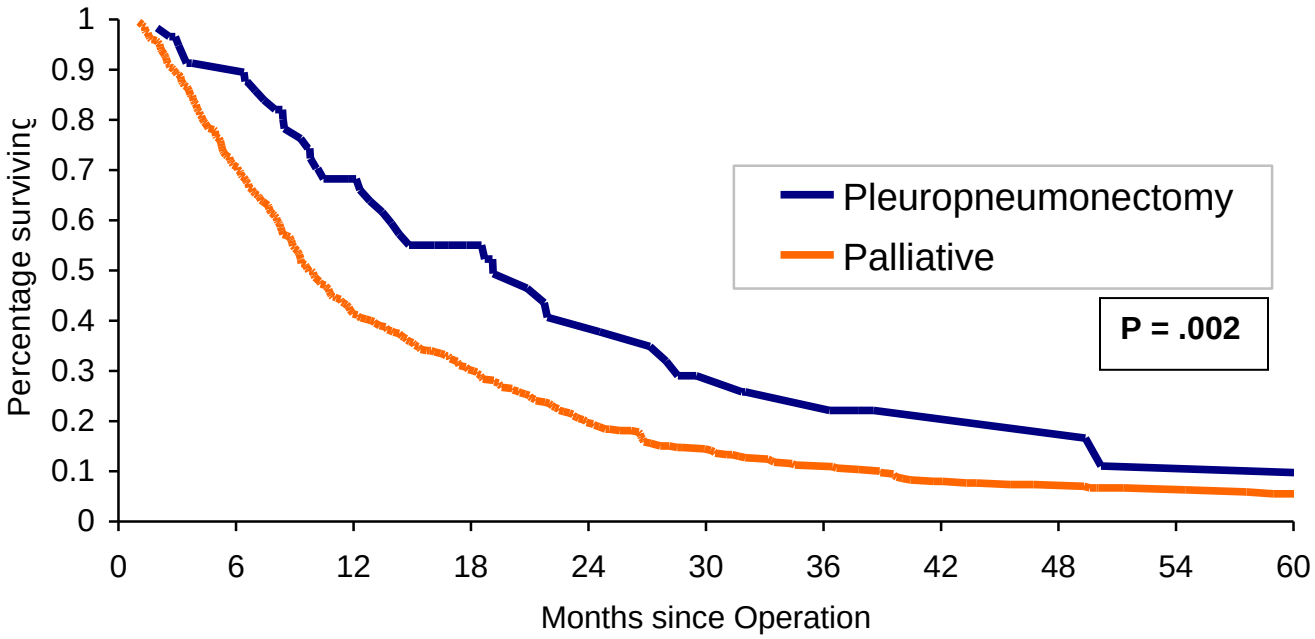
RADICAL PLEUROPNEUMONECTOMY

Patients	**62**	
Age	**22 – 74** years (median 58 years)	
Sex:	**51** males	**11** females
Side	**31** right	**31** left

Postoperative mortality: 6.5 %

Postoperative morbidity is commonly; prolonged hospital stay related to bleeding, renal impairment, arrhythmias, infections, and abdominal complications.

MESOTHELIOMA – MEDIAN SURVIVAL
(Radical surgery versus Palliative Surgery)



RESOURCE MATERIAL – SOURCES AND WEBSITES

Reading

"Life After Pneumonectomy: Common questions and answers".
A patient information sheet- Jocelyn McLean.

"Living Life after Pneumonectomy" – Summary of Masters Research Thesis titled Recovery following pneumonectomy: Patients' initial 2-year experience (2002), (University of Sydney) - Jocelyn McLean

"Preparing for Lung Surgery". A patient information handbook - Jocelyn McLean.

"Climbing out of the Big Black Asbestos Hole" (2004). Elizabeth Thurbon.

"It's not about the bike: My journey back to life", by Lance Armstrong.
An inspirational book about an illness journey and recovery.

Websites

Sydney Cardio thoracic Surgeons **www.scts.com.au**

Phone (02) 9550 1933

Professor Brian McCaughan
Mr Nick Hendel
Mr Michael Wilson
Mr Matthew Bayfield
Mr Paul Bannon

Asbestos Diseases Foundation of Australia (adfa) **www.adfa.org.au**

Phone (02) 9637 8759 **Free call 1800 006 196**

Adfa provides information and support on all matters pertaining to asbestos use and asbestos related diseases such as dealing with asbestos claims, managing asbestos in the workplace and safe removal of asbestos for the home renovator. They host a number of support groups – please contact adfa office if you wish to contact a group near you. Their booklet titled **'Understanding Asbestos Diseases'** provides a brief but succinct in its information.

Dust Diseases Board of NSW (DDB) **www.ddb.nsw.gov.au**

Phone 1800 550 027

The DDB statuary function is to administer the Workers Compensation (Dust Diseases) Act 1942-67. The liaison staff at the Board will answer questions and provide direction about compensation issues that arise from work place exposure to asbestos. Do not be afraid to pick up the phone and talk to them.

The Cancer Council New South Wales **www.cancercouncil.com.au**

Help line 131120

The Cancer Council provides information booklets on all aspects of all cancers (free of charge) and their staff is well trained to answer questions you may have. They run a telephone support group (free of charge) for lung cancer patients and carers. This is ideal for the country patients who feel isolated and are isolated from metropolitan cancer services. This service is highly recommended.

The Australian Lung Foundation **www.lungnet.com.au**

Phone (07) 3357 6388

The Australian Lung Foundation is an organization that is responding to the need in the community to reduce the significant and debilitating cost of lung disease, both in human and monetary terms. They provide patient information leaflets related to the many lung disorders such as lung cancer. Alpha-1-Antitrypsin Deficiency & Lung Disease, Asbestos Related Lung Diseases, Better Living with COPD, Bronchiectasis, Bronchoscopy, COPD: Chronic Bronchitis & Emphysema, The Common Cold, Corticosteroid Therapy in Respiratory Disorders, Home Oxygen Treatment, Influenza, Interstitial Lung Disease, Lung Transplantation, Obstructive Sleep Apnoea, Sarcoidosis, Silica Related Lung Disease, The Lungs, Tuberculosis. If you cannot access this website then please ask the case manager to do so for you.

Sydney Cancer Centre / Support services **www.sydneycancer.com.au**

There is an established Psycho-oncology service that provides support and counseling for patients, carers, and families who are having difficulties in coping with social, emotional and physical consequences of having a cancer diagnosis. You may contact the case manager who can make a referral to the service for you or a self referral will be accepted on (02) 9515 6677. Lung cancer specific support services are being developed. If you are interested in attending a lung cancer support group then please contact the case manager who will refer you on to the appropriate person.

Within the Sydney Cancer Centre is the Telstra Information and Support Centre on Level 3 of Gloucester House - patients, families and friends are welcome to use the library resources and participate in activities such as Yoga and Relaxation, and painting sessions. Refreshments are provided.