

Story Number 1

Jim Holmes is a doctor of psychiatry. He received the diagnosis of his mesothelioma while attending a patient. This is his story.

Transcript

This transcript was typed from a recording of the program. The ABC cannot guarantee its complete accuracy because of the possibility of mishearing and occasional difficulty in identifying speakers.

Robyn Williams: We begin on the evening of November 24th 2007.

Kevin Rudd: I also want to make special mention tonight of Bernie Banton. Bernie, a fighter for the victims of asbestos, I say to Bernie, if he is watching this broadcast, mate, you're not going to be forgotten in this place. The values for which you have stood and fought, Bernie, you stand out as a beacon and clarion call to us all about what is decent and necessary in life and, mate, I salute you.

Kaylee Banton: I have a dream that one day on the steps of Parliament House the sons of former James Hardie workers and the sons of former James Hardie owners will be able to sit down together at a table of brotherhood. I have a dream that one day even the state of NSW, a glorious state, sweltering with the heat of sickness and asbestosis will be transformed into an oasis of morality and justice.

Karen Banton: Bernie used his God-given gifts to secure justice for thousands of people against the greed of a corporate giant. Fittingly, his favourite Old Testament character has for many years been David. The 'never take no for an answer' attitude of Bernie Banton brings hope nationally and globally that good will always triumph over evil.

Robyn Williams: The Prime Minister on election night, followed by 12-year-old Kaylee Banton and Karen Banton, granddaughter and widow at Bernie's funeral on Wednesday. David against the Goliath of the asbestos industry. I actually remember how severely we were castigated in the ABC science unit back in the 1970s when reporter Matt Peacock, now with *The 7.30 Report*, first covered Australia's dreadful record with asbestos disease. But what is it like to get symptoms apparently from nowhere? How do you deal with this kind of ghastly death sentence? Today we begin an occasional diary kept by a country psychiatrist Dr Jim Holmes who lives near Kempsey in central NSW.

Jim Holmes: Life is good. Thankfully I remain an optimist despite events of the past three years. I am a rural psychiatrist and was working both in the public hospital system and in private practice. I was happily married with plans for the future. Then the bombshell exploded. In March 2004, the day before my 60th birthday, my wife Margaret was diagnosed with a relapse of the breast cancer for which she had been treated eight years earlier. This time it had spread to her bones and diffusely through her lungs. In the following ten months she taught me a great deal about dying-and living. After the initial shock dissipated, she seized upon her situation as a challenge.

Margaret liked a challenge. Through life she had set herself a series of challenges, or projects, usually with positive results.

She embraced a series of chemotherapies to extend her life as best she could. Although the side effects were at times severe, she was determined to travel and enjoy what time she had. With wheelchair and oxygen we visited friends in Queensland, took the family to Lord Howe Island, and toured Tasmania and the Northern Territory. In our travels Margaret road-tested numerous hospitals, where she received chemotherapy or treatment for the occasional infection, but she always remained undaunted. Between trips she inspected several funeral companies. Margaret also ensured that the crematorium was to her liking. She ordered the cheapest chipboard coffin and before Christmas the family came to a pre-wake in which we celebrated her life and painted the coffin. Margaret died on Australia Day 2005. Happily, just two weeks before, we spent a weekend at a resort where we had stayed at the beginning of our relationship. Though very weak, almost confined to a wheelchair, and needing oxygen, Margaret continued to make the best of it. She even booked herself in for a massage and facial!

During that last ten months we often grieved together. Many bittersweet tears were shed and I am sure this made my ultimate bereavement more bearable. I had lived alone at times in the past and was quite self-sufficient. I coped again and returned to fulltime employment. I also threw myself into singing which, thanks to Margaret, I had discovered some years previously after a lifetime of believing I couldn't. I took lessons and joined a choir. It is wonderful to gain an appreciation of a piece of music from the inside and the end result is exhilarating. For over two years I was content to live in peaceful solitude before considering the possibility that I might eventually find another partner. I envisaged a life of extensive travel after retirement in 2009. That gave me over two years in which to prepare patients and wind down my psychiatric practice. I expected to live to my 90s, or at least my late 80s, like most of my family, but yet again fate wrested control of the steering wheel.

I spent Christmas last year with my adult children at Byron Bay. It was fabulous to enjoy Christmas with three generations together. No sooner had I returned home than I developed pneumonia. I had experienced a similar episode six months previously following a flight from London. I attributed this to the airline's onboard germ share program. The illness was mild and cleared after a few days on antibiotics. My second episode felt no more severe but was more persistent. It didn't stop me working and being a doctor, its mildness rang alarm bells. Recurrent pneumonia is often associated with underlying lung cancer. You can imagine my relief when the X-rays revealed nothing sinister. However, I developed a pleural effusion, a collection of fluid between the lung and the chest wall, which impaired my breathing.

In February a CT scan showed nothing apart from the effusion which was assumed to be post pneumonic and in March 1.5 litres of straw-coloured fluid was aspirated via a needle in the back of my chest. Analysis of this didn't find anything nasty, but another 1.5 litres had to be removed in April and a smaller amount in May. By this time the pleural space was becoming loculated; that is, partitioned by fibrous adhesions which impeded the drainage of fluid. At this stage, my physician sent me to a thoracic surgeon in Sydney for an exploratory operation. He took numerous pleural biopsies and left a drain in my chest for three days before sending me home. He told me that

the outside of my right lung was extensively inflamed. He said he was unsure as to the diagnosis but was sending the biopsies to Adelaide, to an expert in mesothelioma.

Up till then I had held wishfully to the conviction that my condition was inflammatory in nature. I would even be happy with TB which was also consistent with the clinical picture. In retrospect, the surgeon's serious expression belied his claim to ignorance, but I was happy to be deceived. The appalling truth was delivered by telephone two weeks later, one afternoon at work, half way through seeing a patient. It was definitely mesothelioma. Not surprisingly, after receiving the news, my concentration was less than adequate for a while.

So, my early suspicion was correct; there was an underlying cancer; but I never imagined it would be the dreaded 'meso'. How on earth could it be? I had never worked with asbestos and couldn't recall any significant exposure to it. But then there was that ceiling that collapsed in 1972. We were living in a recently renovated Rozelle terrace. I was setting off for a hernia operation, as one does, and closed the front door rather heavily resulting in a pile of debris and a cloud of dust. It was a lath and plaster ceiling and I still don't know if it included asbestos-but maybe it did.

In July I kept an urgent appointment with an oncologist in Sydney who had expertise in mesothelioma. He confirmed what I already knew and said that maybe 5-10% of cases occurred without exposure to asbestos. He also said that life expectancy was eight months from diagnosis. After a further CT scan, I was told it was too late for an operation to remove my right lung and pleura. I wasn't sure whether to be pleased or disappointed. However, my right lung was no longer an asset. Collapsed at the base, encased and constricted by a thickening 'rind' of mesothelioma, I envisaged my lung as an empty goatskin flask which had lost its elasticity.

Following my return home, I retired medically and embarked on chemotherapy with my local oncologist. I knew him before through his treatment of Margaret but I hadn't expected to occupy her chair. I greeted him with a wry smile and listened to his prognostications as though he was talking about someone else. He benignly explained that years ago there was no good treatment for 'meso'. They used Cisplatin (a compound of platinum) but with unremarkable results. Then, a few years ago, along came Alimta, a drug that blocks certain enzymes utilised by the cancer to grow. The good news is that it can extend life by several months and sometimes longer. The bad news is that when it stops working there is little that can be done apart from palliative care.

With characteristic optimism I attended for my first treatment at the end of July. This consisted of an infusion over a couple of hours. When it was done, one of the doctors attempted to aspirate more fluid from my chest. Unfortunately, all he got was blood and air. He had punctured my lung resulting in a pneumothorax, a leakage of air into the pleural space. This further collapsed my lung and exacerbated my already impaired breathing. The air is gradually reabsorbed but it takes several months.

By this time, my dear daughter Bryony had moved in to help me. I am so grateful to her and don't know what I would have done without her. Over a few days the effects of the chemo became apparent. Fortunately I didn't experience the nausea and vomiting suffered by many, but was overcome by extreme fatigue and loss of energy.

For a couple of weeks I could do little apart from rest and read or watch television. I consoled myself with the thought that if the chemo made me feel this bad, it must be making the cancer feel even worse, as though it were some kind of alien creature eating me from the inside. Eventually my system recovered and I felt almost well again for a few days before the next of my three-weekly treatments was due. Before my third treatment I had another CT scan which showed 'some shrinkage of the rind'. In other words, treatment was working and it was worth proceeding with the next two courses.

Over time I seemed to adapt to the effects of the chemo. Possibly the physical effects were the same but having learned to live with it, I suffered less and was able to do more, though not much. I was able to attend a conference for country psychiatrists in Byron Bay, at least when I didn't have to lie down during the day. I even enjoyed an afternoon of whale watching. Then came the next CT scan. The rind was no longer shrinking. The chemo was no longer working. Oooh shit! I steeled myself for the oncologist's blithe pronouncement that he would 'give my body a rest'. Despite the disappointment, I had to agree that there was no point in poisoning myself for the sake of it. It's now several weeks since my last treatment and I'm feeling a lot better, thanks for asking, though my breathing has not improved, and I doubt that it will. Even getting dressed leaves me panting. Nevertheless, I am still singing. The tone and power are not affected; I just have to take more frequent breaths.

Having a life threatening illness is not all bad. I have not been depressed and have an increased awareness of the value of each day. I enjoy every minute, almost. Priorities change. Material aspirations lose importance while relationships gain. I have been amazed by the amount of support given by so many people; by family, friends, colleagues and patients. People have said I shouldn't be so surprised, but I have always been beset by self doubt and it was wonderful to see such an affirmation of one's value. For many weeks any expression of support brought tears to my eyes, and still does at times.

Now that I'm feeling relatively well, I've booked a flight to the UK to see my remaining family and old friends over there. Bryony and her daughter Jasmine will come with me though my oncologist thinks I will probably remain well for that period. In the meantime, I am booked into Petrea King's *Quest for Life* residential program to gain a dose of inspiration to better manage my life at this stage. I intend to make the best of everything.

Robyn Williams: Dr Jim Holmes. He'll return in two weeks with his second 'meso' diary.

PART TWO

Robyn Williams: Asbestos has been on our minds this year sadly. Dr Jim Holmes began his 'meso' diary on *The Science Show* two weeks ago. That weekend he actually sang in a performance of *Messiah* at Sydney Town Hall, despite one lung being destroyed by mesothelioma. Jim Holmes is a country psychiatrist, and here's his second instalment.

Jim Holmes: Nearly four weeks have passed since my last diary entry. During that time I haven't received any conventional cancer therapy, nor have I seen my oncologist. In October he described the growth as dormant but couldn't tell me when the dragon might awake from its hibernation; it might be a few months or several. If and when that happens he could only offer second-line chemotherapy which is generally less effective. I wondered in that case whether it would be worth enduring the side effects for minimal benefit. I set those thoughts aside and determined to get on with life. I enlisted the help of family and friends to clear out my psychiatric practice and bring home the filing cabinets. I culled all files earlier than 1990 and took them to the hospital to be shredded.

I continued with my plans for the trip to England with my daughter Bryony and granddaughter Jasmine. I visited my GP to obtain a letter supporting my fitness to travel and my need for a wheelchair at the airport. The chair is necessary because I can only walk at a snail's pace without gasping for air. Having said that, I am still singing. Two weeks ago I sang in the bass section of a small choir in a performance of Buxtehude and at home I am rehearsing Handel's *Messiah*, singing along to a CD with score in hand. Before I sing I have to sit for a couple of minutes for my breathing to settle. Then I can manage reasonably well, though my phrasing is abbreviated at times.

Recently I spent a week at Petrea King's Quest for Life program in Bundanoon with my daughter Bryony. Petrea suffered with leukaemia in the early 80s and was expected to die within a few weeks. However, without conventional treatment, she threw herself into extensive meditation and other lifestyle changes and achieved a complete remission. Since the late '80s she has devoted herself to helping others with life threatening illnesses. With the help of benefactors she has established a centre with a team of therapists and helpers. The aim is for people to achieve their full potential in life in terms of their spiritual, mental and physical wellbeing. If this results in a remission, that is a bonus, not a primary objective.

I am not a religious person and regard spirituality in socio-biological terms. Nevertheless, whether or not certain phenomena are regarded as spiritual or the result of cerebral activity, the result can be the same. Either way, meditation, positive imagery and attitude can result in improved outcomes, at least in quality of life. The course aims to establish inner peace through meditation, relaxation and resolution of emotional turmoil through forgiveness of self and others. They explain the benefit in terms of the reduced levels of stress hormones such as cortisol, prolonged elevation of which can impact adversely on the immune system. In fact boosting the immune system is a central aspect of the program, to enable one to fight illness more effectively.

To this end there is considerable emphasis on healthy diet and complementary medicine. It was backed up with some science, some of which sounded convincing. In the literature there is a variety of advice which can be quite confusing. We were given a strong message that it is probably not so important which combination of therapies one chooses, but that one undertakes them with full commitment and positivity. In other words, the placebo effect could be paramount. However, if positive attitude et cetera results in less internal stress and improved immune function, this could still

lead to an improved outcome. Given that conventional medicine has little left to offer at this stage, I embraced the alternative as a strange but enticing bedfellow.

Even a few days before going to Bundanoon, I began boiling pawpaw leaves to make an infusion. This was on the basis of knowing someone who had achieved remission this way after all else had failed. Further exploration revealed a wealth of stories extolling its virtues, one of which is certainly not taste. It is revolting, and as bitter as quinine. Traditional wisdom would have us believe that it must therefore be doing us good. I sincerely hope so. Three or four times per day I slug down a glassful of this concoction and follow it immediately with a piece of soft liquorice to mask the taste. Also three times per day Bryony juices a mixture of carrots, beetroot, celery, apple and ginger, which is much more appealing. As a result of this and an increased array of non-prescription tablets and capsules, my system is awash with anti-oxidants and immune system supports, all allegedly attacking my wayward mesothelioma cells and if they're not, I'll want to know why!

I must say, the Quest for Life program was inspiring, and we returned home determined to maintain the changes we had begun. We meditate daily and our diet is largely vegetarian and most dairy products have been eliminated. Where possible we use organic produce to minimise toxic residues. To this end we are growing a lot of vegetables though they are not yet ready for harvesting. Due to my impaired breathing I am unable to do any of the hard work. Fortunately Bryony has attacked the gardening with the zeal of a born-again gardener. She has resurrected the fallow beds which are beginning to look like Peter Cundall's...well, beginning. My job is to stand around telling her what to do and maybe pull a few weeds. I am becoming increasingly redundant, at least in the garden.

The day after our return from Bundanoon was the occasion of a good friend's 60th birthday. As a surprise for him (presumably pleasant) his wife had asked me to sing Leonard Cohen's *Hallelujah* at his party that evening. I rehearsed a bit in the morning with his daughter who was accompanying me on the guitar. It went down very well at the party and everyone joined in the chorus. More impressive, to me at least, was the fact that Bryony and I maintained our resolve. We ate selectively and totally abstained from alcohol; very strange for one who has been known to fall asleep under the table on such occasions in the past. Actually I find it remarkable that I lost my appetite for alcohol four months ago, shortly before starting chemotherapy. Was my body looking after itself? I also lost my appetite for lavash bread, but that was simply Pavlovian conditioning after eating a number of wraps while receiving my chemo infusion. Now I am focussed on preparing for the *Messiah* performance at the Sydney Town Hall and my flight to England the next morning. Hopefully I will manage all right, though my breathing is a bit of a worry. It has deteriorated somewhat over the past months and my inspiratory volume is down to 1.5 litres. Nevertheless, I remain optimistic that I will endure.