

Without Due Care

AN AUSTRALIAN HOSPITAL TRAGEDY

by
Therese Mackay

*The story of a Quadriplegic man's shocking
Medical Abuse and Death at the hands
of the diseased and unaccountable
Australian Health Care System.*

Without Due Care – An Australian Hospital Tragedy.
First published in Australia in 2010 by Therese Mackay.
PO Box 248 Port Macquarie NSW 2444 Australia

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ISBN: 978-0-646-53747-4

Printed by Cooranbong Printing
37 Currans Road, Cooranbong NSW 2265 Australia
Phone 61 2 4977 1111

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Dedication



*I dedicate this book to my daughters Melissa and Alison,
who have suffered too much,
to my sisters Veronica, Joan and Jackie and to my friend Carmel.
Without their emotional support, the quest for justice
and change would be much harder.*

*I honour the unsung heroes of the Intensive Care Unit;
the physiotherapists who really made a difference.
A few nurses and doctors treated my husband with true compassion
and have my eternal gratitude.
The hospital Chaplin was a blessed support throughout.
Thanks go to Dennis Stevenson, Nicola Taylor, Michelle Lopert
and Gill Goater for their patience and help.*

*I acknowledge Sue Corrigan-O'Reilly's invaluable help
in doing the final edit of this book.*

*My story is a memorial to my beloved husband Donald Mackay,
whose death was caused by systemic failures of the New South Wales
Public health system. He died on 17 May 2007.*

Melissa and Alison wrote this for their father's headstone:

*A beautiful man,
who gave and fought for others with courage and strength;
noble, loyal, passionate and determined.
Kept the child at heart and filled our lives with laughter.
So good, yet so naughty; so free, yet so confined.
A beaming smile and twinkling eyes,
his light burned so brightly.'*



Foreword

Medical negligence is a subject no one wants to talk about until it happens to them.

It is made all the worse for affected families because Australia's health system is saturated in cover-ups; a system so ruthless it does not matter if trusting patients end up dead.

When our loved ones die from their medical treatment, it is human nature to want an all encompassing explanation on what went wrong. The duty to our loved ones kicks in and drives us. We expect statutory authorities to act.

Therese Mackay, in demanding answers to 'what went wrong' with her late husband Don's treatment and care in a Sydney public hospital that led to his untimely and unnecessary death, was not only blocked by people with greater resources but also not helped by those people whose help she needed because of their institutionalized indifference.

No bereaved family with iatrogenesis the cause of death should have to steer the investigation to find the truth. The Mackay family so did. But those people in power who failed to exercise their statutory duty and do what is right did not consider that the Mackay family's efforts in wanting justice for Don would help others encountering the same tragedy when their loved ones too die from medical negligence.

The New South Wales health system let Don Mackay down. His family did not.

This is an account of a loving family's plight and fight for justice for the late Donald William Mackay 1950-2007.

Lorraine Long
Founder
Medical Error Action Group
www.medicalerroraustralia.com

Sydney
12 August 2010

Disclaimer

I have gone to great length to remove all the names of medical staff involved so as to protect identities. I have also removed the names of the hospitals involved and even of our own home area where possible.

At the end of writing this book I find that the individuals involved who caused so much suffering to my husband Don and to us his family, no longer matter to me, and so have made every effort possible to ensure that no one involved in delivery of medical care will be recognisable to the general public or to other medical staff. They may recognise themselves and if they do I hope they will take on board what I have described in the spirit of change and improvement of outcomes for those accessing the NSW health system. After all the hospitals exist because of the patients, not the bureaucrats nor medical staff.

I have purposefully left out a very serious and disturbing breach of medical ethics witnessed by my sister, my daughter and myself. I have done this after much soul searching and with full agreement with our family. My reasons for doing this are so as to not hold up the publishing of this book, legally. Considering the nature of this event it is serious enough to do just that, and in the scheme of things regarding the hospital, will not achieve any positive outcome.

I make no apologies for my criticism of the Health Care Complaints Commission who have failed yet again to give fair and unbiased service to the people of NSW. I believe along with many, that a top heavy health bureaucracy is a major cause of the running down of what was once an excellent public health care system and one to be proud of.

I hope that my story will be used as a teaching tool for those delivering health care, and as a warning for those of us entering the health system.

Therese Mackay.

Prologue

My beloved husband, Don Mackay, died because of what was done to him in a major Sydney teaching hospital: a wrong and totally unnecessary operation; a lung mistakenly suctioned for 22 hours at 10 times the correct rate; a severe MRSA, or golden staph infection inside his lungs; deadly pneumonia and sepsis which developed during the 36 days he spent there.

The hundreds of errors and the numerous instances of lack of caring listed in this book are only those I witnessed or discovered during the 12 hours I was with Don each day for just over five nightmarish weeks. Common sense tells me many more must have occurred while I wasn't there. Certainly during the nights Don had tests, was being turned, had body care, had X-rays taken and experienced medical crises. Other events unknown to me also occurred. For my own sanity I believe it is best that I am not able to find out what else happened to him. What I do know will haunt our family for a long time. For me, it will be for the rest of my life.

Knowing the grievous impact on Don of the errors they had made, senior doctors at the Sydney Hospital effectively imposed a blanket ban on any information getting to us about every aspect of Don's condition, its causes and treatment, alternative options, possible adverse effects of treatment and the probable and actual outcome. Though this may seem an extremely unlikely way for staff of a major hospital to behave, particularly with patients' rights so well defined these days, it is true. Such morally unacceptable conduct needs to be fully exposed to the public and to the authorities, so as to end – I hope forever – what appears to have become standard practice within this particular, once highly renowned, Australian hospital.

CHAPTER 1

How Could They Do This to Him?

In another desperate attempt to end the cruel, painful farce that was being played out in the Hospital's Intensive Care Unit, Don had again bitten through the ventilator tube in his mouth, trying to end his living hell.

"Help me."

Those two words haunt me as I write this today, more than two years since his death. He looked directly at our daughter Melissa and me and on the outrush of trapped air, when the tube was bitten through, came his awful plea. Melissa and I will live with those words inside our heads for the rest of our lives. The reality of Don's desperation and his pleading for help still makes my chest hurt. It is the same for Melissa. This is hard to deal with. That particular night, when I tried to sleep, my heart felt like someone had sawed through it. I lay there raw and bleeding. Hopeless. Helpless. Useless.

We couldn't do anything to help Don, apart from killing him outright in front of them, and that was something we just couldn't bring ourselves to do, no matter how bad things were. I felt terrible guilt over this inability to act. I could have done it, and gone to jail. I can imagine the headlines, 'Woman Kills Disabled Husband.' But the spirit in me couldn't face it, and so the tragedy was left to play itself out.

As before, the alarms went off and we were hurried out so doctors could reintubate Don. And on it went like that, for another five weeks.

If Robin Cook, the author of medical horror stories, had written a novel based on the torment Don endured without choice, he could not have matched the reality of what happened inside the chaos, grime and cold detachment of that major hospital. No one would have considered it credible. People don't really believe that it can have been that bad. Most can only take in the bits and pieces you can tell them.

In Cook's horror novels, there are always one or two villains, deranged doctors or nurses or whatever; but what caused Don's death was no aberration of humanity, no psychopathic doctor or demented nurse. The real horror I carry within me these days is that Don wasn't brutalised and killed by evil, dark forces. No, his suffering and death were caused by entirely ordinary doctors and nurses, most of whom I would not recognise again. No doubt most of them go home at the end of each shift with no idea what their lack of compassion, cleanliness and sense of responsibility mean to vulnerable patients like Don. This attitude carries right through, to the NSW Health Care Complaints Commission (HCCC), which almost always absolves the medical practitioners, and on to the NSW Health Department, the NSW Labor Government's Health Minister and the Premier. No one can be pinned down. No one is accountable, no one responsible. This is becoming 'hospital culture' in NSW, and it chills me to the bone. At times when I was inside the Sydney hospital and since, it was as if we were all characters inside George Orwell's *1984*.

Despite everything, this book is written in a spirit of hope. I am an optimistic person by nature and for me the glass is always half-full. The hope I have in writing this is that all those ordinary people responsible for Don's care in that grimy, chaotic, dysfunctional hospital may read this and realise what happened, how so many of their actions made him suffer and the effect on those of us who loved him. My hope is that each doctor, nurse and bureaucrat who reads this and understands will act differently in future, so that others can be spared the shockingly bad medical and nursing treatment Don received.

Last night, my beloved husband died again in my nightmare. I dreamt I woke up beside Don in our bed. He is suffering and drenched in sweat. I say to him, "I'll get you out of all this." I pick him up like a baby, even though he is taller than me. In dreams all things are possible. Would that this were so in real life. I carry him out to the lounge room to show our daughters and my sisters that he is still here, still alive, although he is once again dying. We still have him. They can't see us. Don and I are like ghosts. So I take him out to the big lounge chair on the verandah, and we sit together. I feel and hear his breath, feel his beard, face and skin, and then the breaths stop again.

He is not suffering any more. I know that. My head knows that, but my heart lies open and wrecked as if it has been cut and hacked apart with a chainsaw. Don's deplorable treatment in a NSW public hospital in May 2007 caused his death. He has received no justice to date. Melissa, Alison and I, who will grieve for his suffering for the rest of our lives, have been denied justice. This book is my testament. Every single thing I write here is the truth, as confirmed by the medical notes and the evidence of other witnesses.

CHAPTER 2

It Begins

Don's story starts with his voice and my remembering our great love. Down through the years of our adult lives, if he was lying awake at night and needing me, or just wanting to check if I too was awake, he would softly say my name, and then again even more softly. I would always hear him, even if I had been sleeping. He said my name so tenderly.

"Therese?" Softly, then on the next breath even more softly, "Therese?"

He said it last night to me, the same, and I turned around in the half-darkness of a moonlit night, as I have done unthinkingly for so many years of our lives. That voice from somewhere behind me, I have loved for over 35 years. It feels like I have known that voice and the spirit behind it all my life. I was wide awake, washed in an overflowing of compassion. I wrapped my arms around myself and fell deeply into the most beautiful sleep. When I woke, in the grey hours of morning, I had a feeling of rightness and knowledge that love like ours never dies. No matter how horrendous the manner of his dying, no one can take that away from us.

I have tried every avenue I can think of to expose what was done to Don. I have tried everything I can do within the system. I contacted our local National Party MP, Andrew Stoner, who has been very helpful; have taken part in a Government Inquiry into the Sydney hospital involved and my husband's death; have participated in an internal inquiry by the same hospital; began a case with the Health Care Complaints Commission; have approached the NSW Coroner's Court to hold an inquest; and have presented all of them with well over 100 typewritten pages outlining the torture my husband suffered. I have taken part in the Garling Inquiry into NSW's public hospital system. On the day I did so, I broke down in the car park, unable to stop my hands from shaking.

I have written letters to editors, and spent too much money with a solicitor to get records from our local doctor and to commission a report by a medical specialist. I spent even more money and time getting hospital records. Then I discovered that the hospital had left out all the X-rays, scans and charts, and I had to spend even more time and money chasing up everything that had been withheld.

I spent three months preparing and collecting signatures on a petition calling for an independent inquiry into Don's death and the cruelty of his treatment. This struggle has taken its toll on me, but there is no choice.

If I do nothing about the shocking abuse my husband suffered and the medical negligence that caused his death, others too will die.

Don was shamefully treated by medical specialists, who broke every procedural pre-operation rule and then some afterwards; by negligent nursing; and by a hospital which was filthy and chaotic. An unnecessary, dangerous operation was performed on him, for no good reason, and it led directly to his death. And during and after all this, there was a breathtaking lack of honesty and openness about his treatment, and a total lack of communication about what was happening. Don's family knows all this now only because we have obtained their notes.

The flurry of activity inside the hospital and outside, in various government departments and agencies determined to cover up the causes and reasons for Don's death, affects me to this day. I was left physically sick, retching at the letter box, after opening and reading a letter from the Health Care Complaints Commission (HCCC) that claimed suctioning Don's lungs at 10 times the correct pressure would not have caused Don any pain "because he was a quadriplegic". On the contrary, Don was hypersensitive to internal organ pain. The pain he endured for over five weeks in the hospital was as if his internal organs were alternately white hot and then ice cold. He expressed this in the lead up to his first respiratory arrest. After that, for the five remaining weeks of his life, he could no longer tell us because of the ventilator tubes first in his mouth and then his trachea, but his pain and suffering became even worse because of what was happening to him in the Intensive Care Unit, or ICU. The Government agencies established and funded by taxpayers to fully investigate medical mistakes are instead acting solely to ignore, cover up, absolve and/or hide in the deepest pits they can find any evidence which may bring the medical system into question.

Six months after Don's death, in late 2007, we sat behind witnesses as they gave their evidence at the inquiry into the hospital and it was hard not to cry along with them for their dreadful suffering. Then I had to get up there and with my daughter Melissa beside me, attempt to convey the reality of five long weeks of grievous medical mistakes, chaos, filth, ignorance, aggression, cruelty and a degree of suffering imposed upon my husband far greater than I ever thought a human being could bear. His five weeks were the stuff of the darkest nightmares, which we still have. If it was a nightmare for us, what on God's earth must it have been like for Don, unable to talk because of the ventilation tubes down his throat and with his arms forcibly tied down to the bed to stop him tearing out the tubing because he wanted to die, knowing all the while that doctors had wrecked his lungs so totally there was no hope?

It is hard for most people to get their heads around the enormity of what happened to Don, because most people can imagine a day or two of dreadfulness, and that's about it. I have had people say to me: "But something like this couldn't happen in Australia". When you tell them that what occurred actually went on for 36 long and appalling days, people frequently tune out, because it's too much to imagine or to accept that here in Australia one of the most vulnerable of people, who had been a quadriplegic for 25 years, could be treated with such a lack of compassion and care.

I am however going to keep fighting for Don as he fought for me and our daughters so many times. I can do this because I am strong. I have been made strong by being loved unconditionally by a man who some might think of as a rough diamond. But as I know, the rough diamonds are the best. His spirit was pure. One of his favourite sayings to the girls was, "Don't take shit."

Well, Melissa, Alison and I are not going to take the shit that the authorities are dishing up to us, to cover up the many systemic causes of Don's dreadful suffering and death.

Understanding Don's Quadriplegia

Some people have the impression that quadriplegia and paraplegia are almost the same things, but nothing could be further from the truth. Paraplegia is impairment in movement and/or sensory function in the lower extremities. With quadriplegia the damage is higher up the spinal column, partly or fully paralysing the arms as well as the legs. The area of the spine affected in paraplegia is in the mid to lower back, in either the thoracic, lumbar or sacral region. Paraplegia involves a loss of sensation and movement in the legs and in part of or all the trunk. Paraplegics generally have good balance and fewer medical problems than quadriplegics, depending on the level of the injury. Generally, the lower the spinal injury, the less the loss of movement and sensation. A paraplegic may be said to have broken their back whereas a quadriplegic can be said to have broken their neck. The higher up the break, the smaller the chance of survival.

Some people imagine that because a person spends all day in a wheelchair, they have no bodily needs such as toileting, showering and the rest. Seriously. We had people sometimes say to us, "And what do you both do all day long?" Or they'd look at Don and go into long-winded descriptions about an ache in their arm or a bit of bursitis in their knee.

Then there is the misconception that quadriplegics experience no feeling below the break, hence no pain whatsoever. This was, for Don as for many other people with quadriplegia, sadly not true. Don endured internal organ pain which he described as:

"On a scale of one to ten, an eight." He was very hypersensitive to this pain.

Don became a quadriplegic in 1982, aged 32, as the result of a work accident. The correct term for his quadriplegia is C5/C6 (cervical) complete, meaning his spinal cord was completely severed between the fifth and sixth cervical neck vertebrae. At the time of his accident, he was a healthy, active young man, which helped him survive the initial trauma. All quadriplegics suffer differently, depending on precisely where the injury occurs, the severity of the damage to the spinal cord and myriad other factors affecting quality of life. Also crucial is the speed and quality of medical treatment and rehabilitation. For Don his accident meant complete paralysis below the break with some weakened and unpredictable arm movement, but no hand movement or feeling.

Don explained his almost total lack of balance by saying: "I feel as if my head and shoulders are balancing on a large blob of jelly." It was often a struggle to hold his position, something it took people – even doctors and nurses – time to fully comprehend. If, when you were dressing Don for example, you let him lean forward in the chair to get his shirt on, he would keep falling forward and onto the floor. He had to be supported from the front, side or back, depending on what the action was. Don had some minor use of his arms when he sat up in the wheelchair, and with a few aids, learned to make the best of it. But once lying flat in bed he was helpless and his arms were almost useless. I always worried about that when others were looking after him while he was in hospital.

For Don, quadriplegia meant that he was permanently catheterised, which caused many problems such as constant urinary tract infections which we only treated when he began to feel really ill. You couldn't treat infections every time, as the antibiotics would have become useless. Many quadriplegics develop bladder cancer, and Don was being monitored yearly for this.

He also had severe osteoporosis, due to no weight being exerted through his bones. His hips were the worst, but hip replacements were impossible because there was no good bone to drill into to stabilise the joint. So Don sat for years, bone scraping bone in his hip joints, and the pain was very bad. He certainly could feel pain, despite his quadriplegia. It used to horrify me to imagine him being turned over in bed by anyone who didn't understand the fragility. I would always turn him with a pillow between his knees, hoping that the hip joint or a long bone would not snap or shear away. But too often while he was in hospital, nurses would be quite rough with him and responded to our admonishments as though we were being fussy. Some treated his serious problems too casually, like playing Russian roulette with someone else's body. His pain was managed for years but never totally alleviated with Methadone (a strong pain medication), which enabled him to get out of bed at least but never really covered the pain. The bones in his feet were as fragile as eggshells, and the fifth, sixth and seventh cervical vertebrae were fused together. The third and fourth vertebrae were badly degenerated, causing constant pain in his shoulders, arms and head.

He had neuropathic or nerve pain which was present constantly for many years and I would sometimes hear him softly gasping when it got too bad. Poor Don.

Most people – even many doctors, it would appear – don't understand that many quadriplegics are hypersensitive to internal organ and tissue pain, even though they may not feel surface pain. For example, many times Don had blisters on his hand from resting it on things he was unaware were hot, yet often he would say that his kidneys felt like they were on fire.

His circulation was not good, so we were careful not to let any infection take hold anywhere, but mostly on his hands and feet. Don lost all his teeth in the last two years of his life, caused by medication which left him with a constantly dry mouth, leading to tooth decay. He had a colostomy because of bowel problems caused by quadriplegia. Most quadriplegics have no peristalsis – the waves of involuntary muscle contractions that transport food, waste matter or other contents through the digestive system – and without this, bowel problems are common and uncomfortable. Don was often in pain from this.

All quadriplegics and paraplegics have to be extremely careful not to sit up in a wheelchair if there is even a slight blemish on the bottom, because by the end of the day, after sitting for many hours, it can develop into a pressure sore. These sores can take months to heal and entail long periods in bed, lying only on the side. In all the years at home, Don never once had a broken pressure sore, but spent many weeks and at one time six months bedridden because of skin trauma. We figured prevention was better than cure, and the time spent like this was worth it, for all the good time sitting up and the ability it bought him to get on with life. Also, when sitting, no folds of clothing could be allowed to dig into the skin, so extreme care had to be taken in dressing.

In common with all quadriplegics, Don had a poor temperature control mechanism. Once he got too cold he would shiver for hours, despite being loaded up with blankets, until eventually his temperature went back to somewhere near normal. If he got too hot, he would just get hotter and hotter, unable to regain control without assistance.

Don suffered extremes of blood pressure. Sometimes it would drop so low, he would just become unconscious right before my eyes. I'd grab his legs and hold them up, while lowering the head of the wheelchair so his feet were higher than his head. He came close to death on many occasions like this. At times, he would also swing from extremely low to dangerously high blood pressure, usually within minutes. This condition, which Don had suffered from almost daily since 1994, is called Autonomic Dysreflexia. Don and I managed this every day and often thought he would not survive, but he did.

Autonomic Dysreflexia is a complicated condition that only happens to quadriplegics. Most have it rarely, some more often and some never at all. Don unfortunately was plagued by daily bouts of this life-threatening condition. Most quadriplegics have a very low blood pressure when lying down; 90/60 or slightly lower and even lower than this when seated. Because of the damage done to the spine, if there is pain from a blocked catheter, an ingrown toenail, bowel compaction, any pain whatsoever, the blood pressure will shoot up dramatically and within 10 minutes or so can reach dangerously high levels. For quadriplegics, 140/80 is dangerously high and if symptoms (pain or pressure) are not relieved immediately a stroke, seizures or cardiac arrhythmia is likely to occur. Don's blood pressure often went to the dangerously high level, and well beyond.

This condition is considered a medical emergency and should be treated as such. In Don's case there were many causes of pain which could not really be relieved. We would check to see that nothing was wrong but then it was a matter of piercing a capsule of a drug called Adalat and getting it under his tongue quick smart. All other methods were too slow for us and we imported this medication from the US. It was difficult to get in Australia once former Federal Health Minister Michael Wooldridge took it off the Pharmaceutical Benefits Scheme. That capsule and Don's and my quick action saved Don's life every single day for the last 13 years of his quadriplegia. We carried an emergency card in case he was hospitalised. When he was in others' care, we both worried because of the lack of understanding in the general medical community of this condition. Too many doctors and nurses assumed Don was just being fussy or hysterical, and they thought that if he calmed down, his blood pressure would decrease. Often they were too slow to administer the Adalat, again endangering Don's life.

With very limited respiratory function, his breathing was laboured, particularly when sitting up rather than lying down because of the altered mechanics of what I call "quad breathing". If there is any fluid or congestion on our lungs, most of us can inhale and exhale more easily by sitting up, but for quadriplegics, it is the opposite. This is important to understand, for reasons that will become clear later. All spinal specialists know that the respiratory mechanism of a C5/C6 quad is different to that of people without quadriplegia. After breaking the neck, or

suffering another illness which affects the spinal column at that level, the body kicks in with a different form of respiration which involves a great reliance on the diaphragm. Quads have far fewer respiratory reserves than the rest of us. They also cough and vomit ineffectually. The dangers this presents are that any cold or infection can quickly become life-threatening, because of the inability to cough up phlegm or mucus. The same goes for vomiting, where ineffectual vomiting can lead to material entering the lungs. Don had been unable to fully expand his lungs since 1982 and his breathing was always shallow.

All this Don had to deal with daily. But life was so good and we lived in the moment, laughing often and getting out and about whenever possible. Don was such a man. He was so brave and solid. With all the above to deal with, he was the very first to help others who were ill or in trouble.

When Don was admitted to the city hospital in April 2007, his complex medical conditions meant he should have been treated very carefully by the cardiothoracic specialists there. Instead, the exact opposite was the case.



Ian, Judy, Jeanette (Tet) and Don aged 1.



The Mackay family 1952.

*Left to right:
Don aged 2, Kathleen (mum), Rod (dad),
Judy, Jan and Jeanette.*



*Don aged 3
at Old Adaminaby 1953.*



*Judy, Jan, Jeanette & Don aged 4
in 1954.*

*Their dad worked on the
Snowy Mountains
Hydroelectric Scheme.*



Don at about 8 with his beloved dog Towzer 1958.



*Don (right) at Moree, NSW with
his cousin Wayne Rushby.*



*Don about 14 at Port Hedland in
Western Australia with a group of friends.*



Don about 18 with his first car called 'Fast Lady' at Blackwater in Queensland in 1968.



Don aged 19.

CHAPTER 4

A Unique Person

Sometimes, in bed, in the middle of the night, I would hear Don softly singing Joe Cocker's *'You are so beautiful to me'* over and over. How do you ever cope with losing someone who loved you like that? Maybe in the night he was awake with pain and just checking if I was awake, which I would be by the end of the few lines he knew, but more often than not he just sang it. Someone able-bodied, who could turn over in the night and hold you in his arms, couldn't have held me as beautifully and with as much love as Don did with his singing and other gestures. It was a way of being close in the dark. He didn't want anything for himself. All he ever worked for and wanted was always for the girls and me and other people. Through that he drew pleasure. I was always beautiful to Don and he to me.

Don was born in Moree, NSW, in July 1950, the youngest of four children. There was Jeanette, always known as Tet, Judy, Ian, then Don. When he was a baby the whole family moved down to the Snowy Mountains, to a town now called Old Adaminaby, because his dad worked for a construction company during the building of the Snowy Mountains hydroelectric scheme. Don's first memories were of many men from different countries painstakingly teaching him to swear in many different languages and telling him to go home and repeat the words to his parents. The men were mostly refugees from many different countries and cultures from war-torn Europe, and most of them had left family behind.

Don and his brother and sisters all remembered this time as magical. Wandering the hills and mountainsides freely; so freely that once they got totally lost. Don was only four, he told me, when the whole Snowy Mountains camp stopped work to look for the Mackay children. His brother Ian said at Don's funeral: "Those six years probably formed Don into the person he became in later years. The things that we got up to as kids would have you sent to a home of some sort or other these days."

What Ian meant was that in the 1950's and 60's, children were allowed a degree of freedom which, by today's standards, the authorities might consider to be neglect. But we all lived as freely as this, especially in the countryside. Ian told a tale about the four of them setting out for the bike ride of a lifetime. "We ended up in a pigsty at the original dam site, with a raging fire that could have burnt an average National Park. Someone volunteered me to get Mum and Dad (Tet, I'm sure) on a raging, stormy, freezing cold night, on a 10-mile ride in the dark. Mum and Dad chastised the three eldest – me included: 'What were you thinking, taking this young baby out in this weather?' As quick as, Tet said, 'Mum, at least Don is warm and dry. And he is not a baby, he is four years old.'"

Two hours before Don died, Ian arrived at our house. He was Don's last remaining sibling. He made a comment about "the shooting" and Don's wasted face just lit up with happiness. Don still couldn't talk properly because of the trachea tube in his neck. Ian later recounted: "Don and I were shooting tadpoles and frogs in a creek near home. I had just shot a frog and Don said, 'Give me a

shot.' I gave him the slug gun and he said to me, 'See how you like it,' and promptly shot me in the foot. That was the start of his greenie attitude. Not content with the foot-shooting, when we got home he loaded the slug gun and chased me around the house."What Ian didn't say is that, as Don chuckled years ago, "Ian ran like a mongrel dog" – which is understandable when being chased with a loaded slug gun cocked and ready to fire.

Later, the family moved to Swansea, near Newcastle, which was where Don developed a lifelong love of the beach. He could swim like a dolphin and he surfed on a long board. Like a lot of the older surfers he used to laugh at the short boards the kids use these days. Don became a 'superstar' at soccer in the Under 14's and was best remembered for kicking a goal for the other team. Ah well, always a darn rebel. Don also had a great and deep love for the animal kingdom, human beings included but especially dogs, horses and birds.

From there the family fragmented, as can happen when kids grow up. Don and his parents moved to Port Hedland in Western Australia, which Don loved. He was a young teenager and had a rich life. He fell in love with a special girl called Judy when they were both about 14. He fell in love with fast cars. He learned how to pull them apart, and then put them back together again. One of his happiest memories was of playing soccer on the beach after work with the Thursday Islanders who worked for the local mining company. He often said to me that no matter what happened, no matter how hot the day or how hard the work, these men smiled and laughed and were the happiest people he had ever met. I would watch Don's face when he spoke about all of this, describing a wonderful tapestry which I still see.

When Don was 15, his dad died from cancer, and he returned with his mum to the eastern states. By the age of 16, he was basically on his own financially, and in every other way. He headed to Blackwater Mines, 400kms or so west of Rockhampton in Queensland, where he worked and learned to live life in the present. It was this quality which Don and I recognised in each other.

His sister Judy lost her husband in a car accident in 1965. His beloved eldest sister Jeanette had married and had a son, Phillip. In 1969, when Phillip was only four and Jeanette was heavily pregnant, a drunk driver hit their car, and they were all killed. Don missed his sister till the day he died. It was Tet's and Jude's photo he looked at so often towards the end of life while in hospital.

When I consider the grief he would have been dealing with, and his aloneness, I cannot imagine what it was in him that still had him smiling so easily. The family that was once so secure had to be so messed up after all this tragedy in such a short space of time. Don was young by today's standards to be so alone in the world. Understandably his poor mum was just battling to maintain her own sanity after losing husband, daughter, two sons-in-law, a grandchild and a little one close to birth. As I grow older and understand more, it is to this family's credit that they did as well as they did. My own dad was killed by a drunk driver in 1969 and I know how that one death rocked our family. I know for Don that there was damage done, but there was nothing self-pitying in him and he just turned his face to the sun, and lived. That was the bravery inside Don which stood him in such good stead in the years ahead.

We met in Newcastle, in the old Star Hotel in Hunter Street in 1972, and joined forces about three weeks after that meeting. It felt lovely, like a sense of coming back home. He was so familiar to me, in a way I have never been able to explain. Melissa was born in 1974. At the time, Don was working for a company installing underground petrol tanks and bowsers all over NSW, and his boss offered us the use of a large caravan so he could be with us while working. Being close and being with family was always a major drive with Don. He craved that intimacy and surety of home and love, which suited me. I was like that also. I think we were both a bit wounded, and having both come from families that didn't neatly slot into the tidy niches of Australian life in the 1950s and 60s, we recognized on some level the same attitudes and values. This isn't to say that it was plain sailing between us. We were both passionate about our feelings and beliefs and there were some really fiery exchanges, even in later years. I wouldn't have had it any other way.

We had a wonderful 18 months in that caravan, and there were few areas of NSW we did not visit. Blayney in winter in an uninsulated caravan was an experience.

Port Macquarie was one of the towns we worked in, and Don was offered work by a local man Gordon Hunt, who had his own earth moving set-up should we ever decide to move there, which in 1976 we did. When Alison was born in the following year, our little family was complete. For \$12 a week rent, we lived in a small house just past Sea Acres, near Johnson's Fruit Shop. Here, we were home. Chooks, ducks, a dog called Boris, cats and Don's horse Lucky, two happy little girls and just enough money made this a happy home for us. Don worked on building sites, drove a backhoe and truck, and was able to turn his hand to most things he tried. Apart from my own dad, few men come up to this capability. Don never thought he couldn't do things. He just seemed to be able to figure out how things were meant to work, meant to be put back together, and away he went. We married in October 1979 because Melissa was about to start school and I wanted the whole family to have the same last name, simple as that. It was a wild, wild, rambunctious wedding.

Then, one sunny day in January 1982, life changed. As Don went off to work, the first day back after Christmas, I recall feeling as if the gods were smiling on me. I had two lovely healthy daughters, a husband who loved us and whom I loved to distraction, a little house. Life seemed perfect.

That first day back at work, Don broke his neck. He hadn't wanted to go, as you don't after holidays. Earlier that day I had taken the girls over to a friend's place. When I arrived back home at lunch time, Don's boss was there, and told me to go straight to the hospital. He didn't tell me much except that maybe it was a broken arm or something. That was exactly what I was told when my dad was killed. It was done to protect us until Mum could tell us the truth. But with Don, I knew immediately something was very wrong. His boss was too serious. I still feel sick when I consider that day so long ago. After all we have been through since January 1982, recounting this brings me more tears than I thought I had left. Even with two little girls, and not much behind us financially, we were all so carefree. It breaks my heart to think of that day and to now know the final

outcome of all his suffering. Occasionally I still find myself wondering “What if... what if he had that day off work?” Just a simple decision.

Don broke his neck in the canals they were building at Settlement City, Port Macquarie. I drive past this place often. Don and a workmate were told to get into the water and get out all the shoring just in case kids jumped in on the weekend. He told me he was happy to be in the water because it was 12 January 1982 and a very hot day. Don could never figure out what he hit when he dived in the water. Before the workmen’s break, the bottom of the canal had been smooth as a swimming pool and deep. Don had been a surfer and would never have gone head first into any body of water where he couldn’t see the bottom. He later thought he may have hit a hump of sand from a dredging operation upriver, which compressed when he hit it. Don was conscious the whole time, which saved his life as he was able to tell people not to move him. Sadly he knew what had happened as he’d once seen it happen to someone else.

He was flown down to a Sydney hospital by Air Ambulance. I had two small children and things to sort out. The girls both knew something was terribly wrong, but I still recall how wonderful they were. Only seven and four, they worked alongside me uncomplainingly to sort out the chooks, the cat, and to gather their most precious things. I recall looking back at the house as I walked away across the cool grass, late that summer evening so long ago. I knew it was home no longer. We caught the night plane to Sydney with the remnants of our holiday money, not knowing if Don was still alive; not knowing where the girls would sleep; not knowing what would happen to our family. As I left our home, I said my mental goodbye. I was to return a month later, but only to close the house down and pack up.

Next morning, a spinal specialist told me straight that Don would never walk again; that he was a quadriplegic and that the spinal cord was completely severed. I was grateful for the specialist’s bluntness, as from there on I let go of foolish, unrealisable hopes, and Don and I pulled together to get the best we could out of the situation. I believe that this doctor was being compassionate in the best way he could be. He also told me that it would be “a long haul”. I remember this as if it is still happening. I used it as the title of a story I had published many years ago. It was to be a long haul, but the haul was full of love and it was in no way long enough for either of us.

Don stayed in the Spinal Unit for seven months. Melissa, Alison and I moved to Sydney for that period, living near the hospital with my sister Veronica. After seven months we came back home, but to a different place. Our lovely little home with its ducks and chooks, cats and dogs, had stairs... and with Don in a wheelchair, now we needed somewhere that didn’t. For years I would dream vivid dreams about our first home, and in my mind even now I feel it’s tucked away where the angels are taking care of it for us.

After a settling period, Don and I became involved in issues in which we believed passionately. He lobbied the local council in the 1980s for better wheelchair access and struck a deal with them that he would go halves in the cost of construction of wheelchair access at major points around the city centre. He just needed to be able to get about and do business in town. The gormless

council shocked me by actually accepting \$7,000 from a disabled man. Everything has its price, especially if you are unable to walk.

Don had received a reasonable and fair but not excessive settlement because he was injured at work. Thankfully he had a decent solicitor in Michael Ryan who gave him good financial advice and treated him with dignity and fairness. With the settlement Don bought a home for us all, purchased a commercial building and kept that building fully tenanted for almost all of the 20 years we owned it. He paid for all his own nursing costs and all his own equipment as he believed and rightfully so that by doing so he freed up the system for those who could not pay. He was incredibly ethical this way. We lived carefully, and had to count the costs as even though the building was there, it had to be fully maintained and revamped regularly and we could not afford not to have it run down or lie empty. We sold it in 2006 and had one year of not having to worry about tax time and GST. Because of his good planning and pure luck at times, we were able to replace equipment as it wore out. We could help our girls as they trod out into the world. Theirs had been such a different childhood and I am pleased to see that they carry the same sense of ethics as Don held. He was a good dad and husband and made sure we were looked after as much as he could. I didn't realise that in the last year of his life he was quietly setting things up so there would be not too much stress financially, and it humbles me to recall how he went about this without my realising.

In the early 1990s he manned an RSPCA hotline and was passionate about his commitment to this. Although Don was not a great cat lover, he abhorred cruelty of any sort and would too often be upset by the callousness of human beings to their pets and livestock.

He not only looked out for his mother until her death in 1997, but also my mother, and was always quick to see when others had difficulties. He had a great compassion for those who were suffering illness or other problems. When his beautiful sister Judy was dying from cancer in Queensland in 1998, he and I spent the last three months with her, only leaving a few days before she passed away. This was a special time and he spent many days just quietly sitting by his sister's bedside, talking and laughing about family.

Don believed ardently in the right of the individual to freedom of choice regarding fluoridation, and other social justice and health issues. He was very active in the fight against the privatisation of our local public hospital and he worked tirelessly for years to have the hospital returned to public hands. Unfortunately he was stuck in bed on the day in 2004 when the hospital was finally handed back to the people of NSW. As was his way, Don spent that morning harassing the local media into speaking with Hospital Action Group members who were there from the beginning of the fight in early 1992, and his hard work on the telephone gained us excellent media coverage.

One good friend, Alan, stuck with Don after his accident, when all his other workmates dropped away, sadly only making their presence felt at his funeral. This long-time family friend died about two years before Don. Most men had real trouble dealing with Don's condition, but Alan and Don spent many an hour arguing back and forth on the phone, swearing away at each other and talking about everything. When Alan died, we were both heartbroken.

In 2004, we moved out to our own 'Craggy Island'. The sense of peace and beauty we both felt the first day we saw this place is still here, and for me it is the essence of Don. I feel so safe here, among the birds and trees he loved so much. On those few days when Don was pain-free, he would comment how wonderful the day was. As the years went on, though, his pain became much worse. His courage and endurance, still being able to be concerned about others, smiling, fooling about, being involved and interested and most of all never complaining, was truly wonderful to experience. It was heartbreaking at times when people did not understand his fragility and his exhaustion, and the bravery he showed by just facing the days at times.

Our family is so aware of the many roles Don played in life – and also on the small screen in our family videos. With just the donning of a wig, or a hat, he would transform into little fat Edie from *'Picnic at Hanging Rock'* (which we re-filmed as *'Picnic at Don Rock'*) or his Mafia alter ego, *'The Don'*. And then there was the eighth day of the week, *'Don Day'*, which was a special day for the kids. All things were possible on this day. Don would declare when it was *'Don Day'*, I think between Sunday and Monday. The force of his personality and its many facets became something of a miracle to Melissa, Alison and me. He was constantly concerned about our welfare, and that of the extended family. The more he suffered the more compassionate he became.

Melissa and Alison joke about the fact that they quickly learnt never to say they were bored because when they did he would give them jobs to do, like weeding. Now, as adults, they say they are grateful for this. He was fiercely independent and a gentle and concerned husband and father. Don lived with dignity and concern for others, but most and more importantly with humour. He had a great sense of compassion and empathy for others: we all experienced his sense of fun and stirring; his generosity; his unpredictability; his intense love of the natural world. But more even than all this was the love he had for Melissa, Alison and me. He loved us without condition.

Melissa says:

"Whenever I think of him it always makes me smile and a million memories come rushing to me; each one making me happier. Dad had a wonderful sense of fun and a wicked, wicked sense of humour. Which left a lot of people not quite sure; was he laughing at them? That made it funnier. Alison and I from a young age absolutely loved when he was being wickedly funny. Kids love it when someone can get away with saying and doing things naughty. We had some amazing times as a family. You couldn't ask or wish for a better dad. He was always, always there for you, and nothing was ever too much. The gap in our little family is going to be felt, but he is always with us, because he promised me once. I remember when Dad was in hospital; his arms were tied with restraints. Mum and I untied them and he stretched out his arms like he was going to fly away. I said jokingly, 'You're free!' And he laughed and smiled. It was the most beautiful smile. So I hope he is free and still has that beautiful smile that I'll never forget."

Alison says:

"We had such a fun and rich childhood; there was always much laughter in the house. There were always lots of cuddles, 'interesting' games of Monopoly (we all cheat like crazy and play Mackay's rules), jobs if we admitted boredom, and there was always a

right way to do jobs and a short time in which to begin them. That was just Dad and it became slightly amusing as we got older. We have so many funny home videos of us four and others, but by far the best was our 'Picnic at Don Rock'. Dad played Edie brilliantly and we have so many one-liners from it that will always make us laugh. Dad always tried to make things better for me. All the phone calls over the last few years I will cherish. All the stories he told, all the silly voices we did. Dad taught me how to cope with things that were beyond my grasp, and always when the seriousness was over he'd get me chuckling again."

Don was so proud of Melissa and Alison. No matter how ill he was down through the years, he would have walked on broken glass to make sure they were OK. Sometimes out of the blue he'd just buy them something pretty he'd find down the street. He loved to surprise us. Sometimes it was just a little bit of cake he'd bring home that had taken his fancy, or a huge Anzac biscuit we had to halve. In later years he began to buy me little bits of gold. A bangle or a chain. As the girls said, "Mum, he was bejewelling you." I'd never been a jewels type person and he knew this, but what he gave me was so right. We seemed to have arrived at a place where we were inside each other's hearts and we knew.

Don's personality was unique. There was nothing middle of the road about him. I know I have been the luckiest person alive to have had the experiences I have had with someone like him. As many people didn't like Don as liked him, so the balance is struck. They may have been surprised that he was streets ahead of them and could spot dishonesty, hypocrisy and ignorance with almost psychic ability. He couldn't hack snobs and truly believed in an egalitarian society, "where all people really are treated equally". Not being one to suffer fools gladly and being fond of calling a spade a spade, people – men in particular – didn't know how to handle a man in a wheelchair forgetting his place. Don could always spot a rip-off, be it a builder who cut corners, or if someone had laid the guttering crooked. He was like a bulldog until he got fair dealing for money paid. It always surprised me how many people would react angrily when their shoddy work was pointed out to them.

But it was only yesterday, when I was remembering a Dylan Moran concert – Dylan Moran is the main character in the ABC comedy show *Black Books* – and it hit me that it's the look Dylan gets in his eye just as he's working up to something. It's a 'black' humour thing. There is almost a little flash in the eye... maybe a twinkle, but twinkle sounds too good and pure. There is a definite 'shift' and if you miss it, you will never get the joke. I have seen Billy Connolly and Dave Allen with exactly the same look. Then I realised that the humour is uniquely Celtic humour and black as it comes. It's clever and complicated and involves a lot of thought. There is an old saying about the Irish: "Just because they are smiling at you doesn't mean they like you." As with the Scots, the Irish suffered many hundreds of years of oppression and learned to dissemble and to get under the radar for survival. Something of this is glued to the humour and if you don't get it you never will. It's important for me to explain this, because it's what kept Don and me sane during the long weeks of his dying.

Once or twice, when he felt temporarily flush, he'd send the girls a few hundred dollars, for no reason. This went to buy winter clothes, or replace things,

and the girls never expected anything like that. It was his way. It was the joy he got when he sent it, knowing it was on its way to them and knowing that they would have a little spend. He got more pleasure out of this than buying stuff for himself. And although some thought that heart had some rough edges, it was those rough edges, that prickly exterior, which made us love him the more, because we all knew inside that exterior was a strong but gentle man, like a chieftain of the clan. A man who took responsibility and who you knew would be there right behind you, no matter what. Sometimes in my mind's eye, I could picture him standing up tall, protecting his people. I never told him this; it was just an image I held.

Our world was so precious to us but it was terribly fragile, and we knew it. Don knew it was unlikely he would live many more years. I knew and 'accepted', as much as you can accept, that this was fact. In early 2007, our older daughter Melissa was preparing for her wedding, a celebration that was extremely important to Don not least because he knew it was unlikely he would live to see Alison's. It was unlikely he would ever see grandchildren. He and I would not grow old together. We had lived with this knowledge since he first broke his neck in 1982.

But he would not have died – just two days before the date originally set for Melissa's wedding, as events turned out – had it not been for what was done to him in the Sydney hospital in April and May 2007. Don would have been alive to escort Melissa down the aisle, as he was so intensely looking forward to doing.

This book is my way of giving Don a voice, to record the injustices done to him and to bring home to those responsible the reality of what their actions did to one remarkable human being and his grief-stricken family. Don's life was worthwhile and we all loved him dearly, but it was he who projected love onto us all. For that we will always be grateful, and will miss him forever.

Medical Treatment Locally.

Professor DuFlou wrote in his report to the NSW Coroner, “it is most unlikely that the deceased’s rapid, but lengthy, deterioration would have commenced when it did but for the patient undergoing the various transfers and treatment.”

In February 2007, late one night from the darkness, Don told me: “If I am ever forced to go back to (hospital name removed), I won’t come out.” He told me that if ever he was on a ventilator and unconscious, I was to ask the doctors to remove him from the ventilator. He told me he wanted to die here at home, and to be able to stay here for some hours after he died because he loved our little place so much. He spoke about not wanting to be cremated and said I was “never to bury me in Port Macquarie.” He was concerned he might die in hospital, and had a terror of morgues. He was especially fearful of dying in that Sydney hospital. All this, from a man who would never normally talk about death.

My strong man broke down that night and spoke about a traumatic incident in his childhood, when he was about 10. He had raised this, only a few months before, for the first time in our 35 years together. Our daughters and I know what this is, and only one other person. It stops there. But that night he just cried like a child, and I held him like a child. He talked and talked. There was just one head on the pillows that night, just one heart beating and a love too deep to climb out of; not that I would ever want to. Don and I were always passionate with each other, with life, with everything we did. We were passionate parents and I thank all the powers in heaven that I was lucky enough to have the time I had with someone who was such a full, rich human being.

At the time, Don didn’t know what was wrong with him, but he was becoming so breathless it was visible, and had been so since early December 2006. The medical care he was receiving locally had not helped.

What happened locally, many people living in that area have experienced, such as a lack of continuity of care, lack of specialist expertise, lack of action and more. In Don’s case, as we eventually discovered, this lack of timely intervention had allowed a build-up of fluid in the pleural lining of one of his lungs – the cause of which was never to be ascertained – to worsen. The oxygen deprivation that resulted left him so tired and debilitated, he would go to sleep sitting up in his wheelchair. But it wasn’t until late February that we realised what was wrong and why Don could not draw enough oxygen to be comfortable.

I had first begun to notice a change in how Don was breathing towards the end of 2006. His chest and shoulders appeared to have to go up and down more to enable him to breathe. It was very gradual, almost unnoticeable at first. Slowly he became a little more tired than normal. By Christmas the laboured breathing was evident to my sisters Veronica and Joan and to our daughters when they visited.

I was in the waiting room at the surgery on the day in January 2007 when Don first spoke to his doctor about his breathing. He had never suffered this sort of difficulty previously, but for some reason, it appeared that the doctor seemed to fixate on Don supposedly having sleep apnoea. I slept beside him all the time, I'm a light sleeper, and I knew full well he didn't have that. Yet Don told me later that even though he complained of shortness of breath, the doctor did not listen to his chest with his stethoscope or tap the chest wall. Had he done these simple diagnostic tests back in January he might have discovered the fluid, and the outcome may have been quite different.

A close friend of ours, Dr Roy Kupsinel, who was based in the US, couldn't believe these most basic tests weren't done on every visit. But Roy was from the older school of doctors who examined, hands on, each patient as a matter of course. He was very alarmed at what we were telling him, but was so far away and, as we found out later, dying from cancer himself. He died just a few months after Don.

The build-up of fluid was very slow. Most of the time, Don was up and about as normal, just very tired. As Don's breath became shallower, he found it harder to get his sentences out. His tiredness was such that some mornings when having breakfast, he'd fall asleep with the spoon in his hand. I began offering to help him, which had never happened before in the entire 25 years since Don's accident in 1982.

After failing to listen to Don's chest and assuming it was most probably sleep apnoea that was causing Don's tiredness, the doctor referred him to the local pulmonary specialist, a doctor who researches sleep apnoea. When Don tried to make an appointment with this doctor, the receptionist asked him to fax a list of all his medications to the office. Then we waited, and waited. Finally, weeks later, we got a response from the specialist, saying he couldn't see Don. I still have that letter of refusal. So much valuable time wasted.

Unknown to us at the time, this specialist did not treat other lung conditions, but his reasons for not seeing Don were never really clarified. Don's doctor appeared disgusted with the specialist's lack of response. At that time in locally there were no other specialist respiratory or pulmonary doctors, and for some reason, it appears Don was put in the 'too hard' basket by the one specialist who was there.

On 26 February 2007, his increasing breathlessness still untreated, Don went for an X-ray and ultrasound prior to routine bladder surgery booked for two days later, and the radiologist spotted the fluid pooled in the pleural lining (a thin lining around the outside of the lungs) of Don's right lung. If Don had undergone surgery with the fluid there, his life would have been in danger, and so the bladder surgery was cancelled.

Once the problem was identified, it should have been a simple matter for local doctors to tap Don's right lung, allow the fluid to drain away over a few days, do biopsies to find out what was causing the problem and then take it from there. But it was a titanic, seemingly hopeless struggle, trying to get any sort of decent care locally. As we fought, Don and I were gradually becoming more and more physically and emotionally exhausted. Our options were running out.

As Don's breathing worsened, Alison became so concerned that she tried to obtain medical oxygen to alleviate his suffering. She contacted the local suppliers

and was told that all they needed was a doctor's referral. As Don's doctor had gone away on a month's leave, Don contacted his partner who was filling in but the request was refused, without a reason given. We were never able to get medical oxygen supplied. I would have liked to hear an explanation from that doctor as why oxygen wouldn't have helped Don to have a little help when he was asleep at night, as I have heard of others having this as a good stopgap.

One example of the lack of continuity of care locally was that both Don's doctor and then his partner went away for a month at this time. They were replaced by a third doctor who had limited insight into Don's specialised condition.

In early March 2007, Don had a partial lung drain in the radiology department at our local hospital, performed by the radiologist and another doctor. They left a fair bit of fluid because they were concerned not to collapse Don's lung by draining it all too quickly. We were home in a day, and Don had a little relief. I understand that it couldn't be completely drained in radiology, as that would have been fraught with danger; but while they had him in the hospital, how hard would it have been for them to arrange a gradual lung drain over a few days? No one has ever explained this to me. For a short while, Don's breathing was easier but he had become so frail that soon he began to struggle again. He just had no reserves left. I recently found a photo taken of Don at this time and even after all that happened I was shocked by how sick he looked – and I had been there at the time.

The young doctor who replaced the two previously mentioned doctors – making him the third doctor in a week or so to see Don – seemed well-meaning, but he clearly had no understanding of Don's condition. Visiting our home, he appeared baffled by Don's whole condition; lacking knowledge about supra-pubic catheters, colostomies and the extreme levels and causes of pain Don endured. And he had no idea at all about the seriousness of Don's lack of oxygen. The evening he came to our house, Don's lips were actually almost blue from lack of oxygen, but this doctor appeared unconcerned. We were left to our own devices. To be in such a position in our home, without any help, was frightening. No one would do anything. Out of desperation we harassed him into finally organising a CT scan, a full month after Don's initial partial drain in the base hospital in early March. A month of inactivity where we were left in our home scared, not knowing what the hell was happening. Later, Don's doctor claimed that arranging the CT scan was the locum's idea, but we know differently, even if only one of us is left to make this record. The third doctor showed no initiative apart from ringing a lung specialist in a town an hour away from our area. This specialist, who had never met Don and had no comprehension of his weakness and limits, was the first doctor to recommend a "Pleurodesis" – a procedure that causes the pleura membranes around the lung to stick together, thereby preventing the build-up of fluid in the space between these membranes. Performed in cases of severe recurrent fluid around the lungs, Pleurodesis involves introducing an irritant such as talcum powder into the space between the pleura in order to create inflammation, which then "tacks" them together.

It was only after Don's death, when I obtained and sifted through all the medical and hospital records that we discovered that that specialist had been the first to suggest Pleurodesis, and that this suggestion had been written down in

Don's discharge notes from the local base hospital. At the time, though, no one even mentioned that word to us.

This specialist was not able or not asked to come to our town to see Don and Don did not have the option of travelling to him by car – even though his original doctor told the Health Care Complaints Commission he did. The reality was that Don and I almost never left our home town. Don's hips were so bad that any travel, sitting in his chair, even to the next town just 10kms away, caused him levels of pain which led to Autonomic Dysreflexia, so we just didn't do it anymore. Travelling even a few kilometres, I would often have to pull over to the side of the road and give Don emergency doses of Adalat to bring his blood pressure down rapidly so he didn't have a stroke. The pain that car travel caused him was intense; so bad his face would blanch. As already mentioned, Don was on Methadone (Physeptone) for pain, but this powerful opiate only covered a part of the pain caused by his crumbling bones. He had severe Osteoporosis and bones as fragile as eggshells in some parts. Some days my poor lovely husband would be grey with pain, never complaining, but I would know, and it would break my heart. So the "choice" was no real choice. If the cardiothoracic specialist could not come to us, then he was unavailable to us. There was never a choice about going to see him.

Once it was clear that no one who was qualified enough to do a simple lung drain and biopsy was available or willing locally to treat Don, transfer to the city hospital became the only available option.

On 10 April, Don went to the local base hospital, knowing he was to be transferred by air to Sydney the next day. Before leaving, Don had a really good look about our place. I stood at the window and watched my husband go up the long gravel driveway in his wheelchair to our front gate. He went right up the path and outside onto the road. Turning back to face the house he just sat. He sat for so long. What thoughts he was having. I could feel his thoughts across that distance, and no doubt he knew as well that I would be watching out the window. He'd been so ill lately, so breathless and often had extremes of blood pressure, I was worried he might pass out in his wheelchair. I imagined him saying, if he had seen me watching through the window, "You silly woman, get a grip". He hated to be fussed over, but he was so sick and we both knew it.

As it happened, everything he imagined and was thinking about that might happen when he went to that Sydney hospital happened exactly and even much worse than even Don could imagine. It was almost like he had second sight.

Don was so concerned at the sloppy care he knew from past experience was coming up, he'd got me to print out multiple copies of all his medications, a copy of which was to be stuck up on the wall near his bed. He knew. He got me to do the same with my contact phone numbers, and our daughters' numbers. He also put on that sheet the medical issues he had, in dot point, so that at a glance anyone treating him would know. He wasn't suffering from paranoia. He knew. I knew. The last time he'd been in the Sydney hospital was enough to have us forewarned and forearmed, or so we thought. He wanted to live and get home and was prepared to fight to do so.

The times that Don had had to return to there in the past (and thankfully, they were few), we would always both be exhausted by the time he arrived, just from

the effort of travelling. That's what part of the dread was about, that and the fact that every time Don was admitted to there, he always picked up Golden Staph infection (MRSA) every time, without exception. This time, he was rightly concerned that this infection might enter his lungs with the lung procedure.

Before Don left our local hospital, a physiotherapist there did a Spirometry test on him. In the results the physio has written "lung age of over 100 years". For a 56-year-old man, this should have rung alarm bells inside both hospitals. But it didn't. A heart specialist who saw Don in local hospital that day noted he had more trouble breathing while sitting up than lying down, something we knew but something which the Sydney hospital's cardiothoracic and even spinal specialists seemed ignorant of, even though it is common for quadriplegics.

Overall, the care before Don was admitted to the Sydney hospital was a disaster. But if we had had an inkling of the horror that was about to unfurl, we would have just turned back home and suffered the consequences. In the event, those consequences could never have been as bad as what happened there. Don left the local base hospital with inadequate and incomplete discharge notes, which left out the vital Spirometry information but casually mentioned the recommendation for a Pleurodesis from a specialist who had never even seen Don, and which Don and I knew nothing about.

Don's death certificate, dated 28 July 2008, states his cause of death to be "respiratory failure due to recurrent pleural effusions and its treatment."

This "treatment", by the city hospital specialists made Don's suffering worse and led directly to respiratory arrest and death. According to the Reports signed by the hospital's Dr. H., doctors operated on Don's lungs without following any pre-operative procedures. This would be unacceptable for an able-bodied person, but for such a weakened person with the complex medical problems that Don had, was inexcusable. Dr H., Director of Clinical Governance at that hospital, wrote in a letter to me dated 2nd January 2008: "The treating team at understood that Mr Mackay was under the care of thoracic specialists in the local hospital, and on this basis assumed that further thoracic review was not required prior to surgery. (Hospital names removed for legal reasons)

But Don was not under such care in locally, and never had been. In medicine, such a thing should never be assumed. People die through such assumptions. There must be written evidence. There was none. Doctors just didn't bother to check. If they had, they would not have performed the operation they performed. And once the operation had failed, the medical team ignored all the very visible signs of that failure, which allowed Don to develop respiratory arrest.

For Don and me, life was so fragile and precious, and every moment we had was special. We knew and talked about all of this in the night time hours. I would often put my hand up under his chin where he still had feeling, and we would go to sleep like this. I did this on the night he died and kept my hand there for some time after, until I felt his warmth leave. I know he knew I was with him until the end and beyond, and knowing this makes it possible not to feel any guilt that I could have changed the outcome of what happened inside the hospital. Don knew. He knew I did my best.



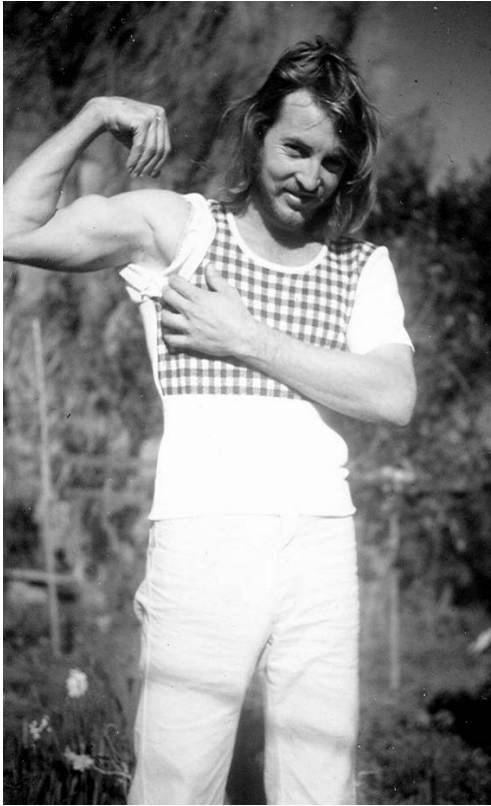
*Don and I at my mother's home in Aberdeen NSW in 1972,
just beginning our lives together.*



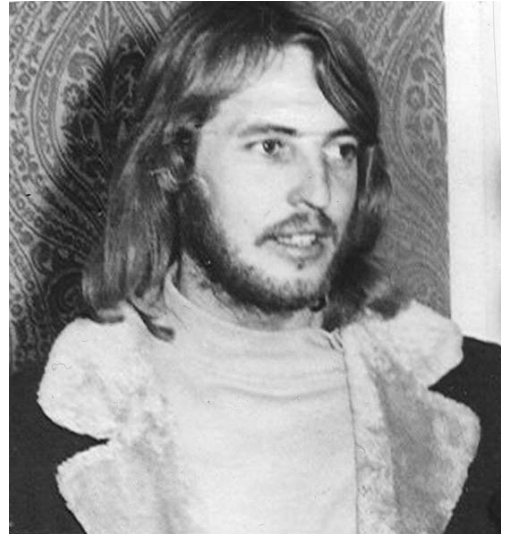
*Don and I, at mum's place
Aberdeen NSW in 1973.*



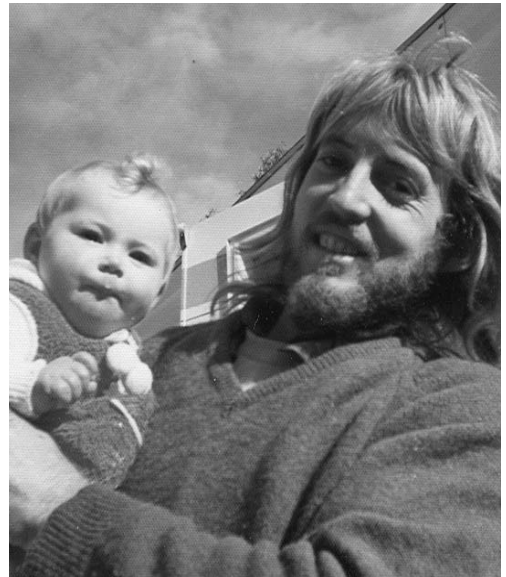
*Don at Mogo Creek NSW working for
Hodge Industrial – installing underground
petrol tanks and bowsers for petrol stations.*



*Don not long before Melissa was born
in 1974 (Cardiff, Newcastle NSW).*



Don in 1974.



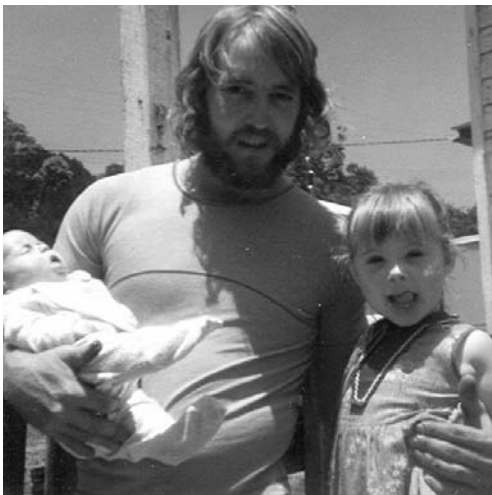
*Don and Melissa
at Blayney NSW in 1975.*



*The new father with Melissa in 1974.
We had nothing and no worries,
but we all had each other.*



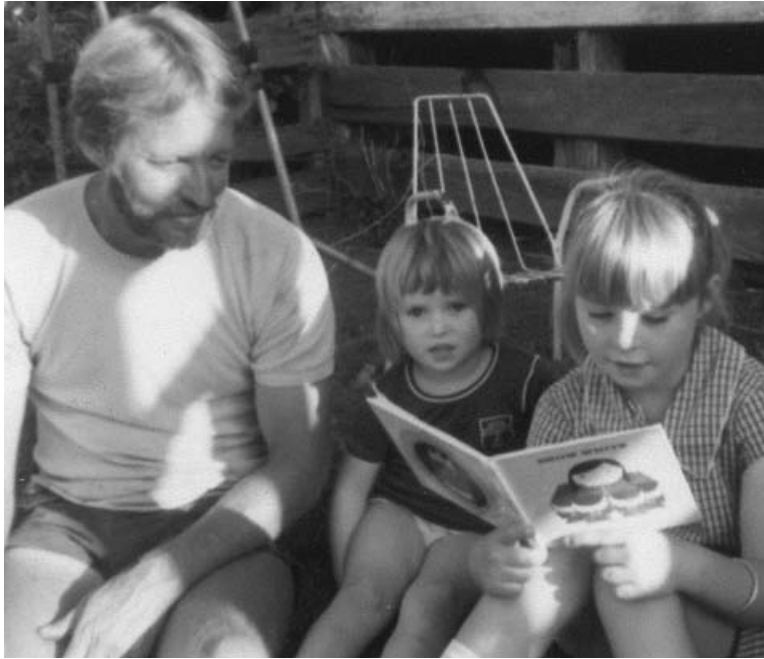
Don in 1976 at Belmont Caravan Park.



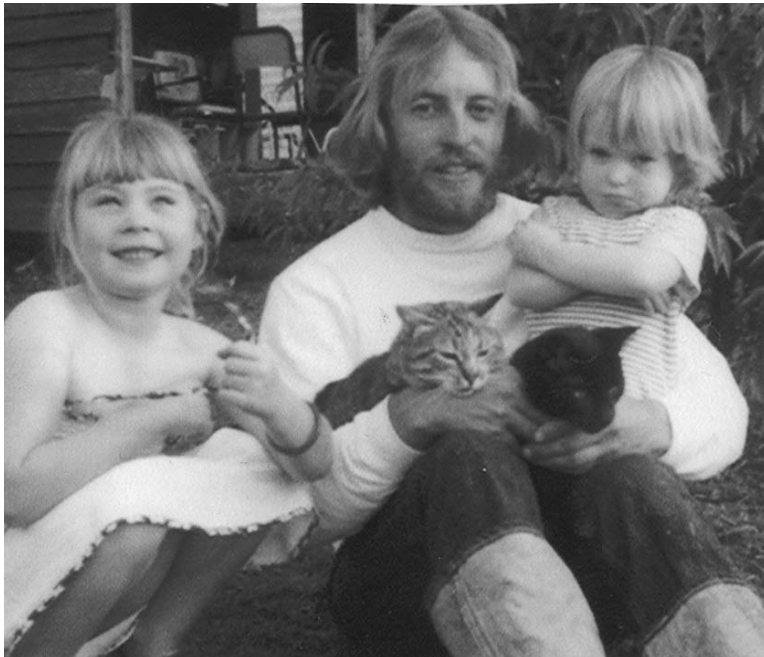
Newborn Alison, Don and Melissa aged 3 at Port Macquarie NSW.



Don, Melissa and Alison in 1978. Just playing.



Don and Alison listening to Melissa reading after school in 1981.



Melissa, Don and Alison with the cats in 1981.



*Left to right: Steven Hunt, Roy Montefiore, Peter Vivian, Unknown, Don and Unknown.
All members of the "Old Bastards Club" which gathered at the old Royal Hotel in
Port Macquarie and raised money for local charity.*



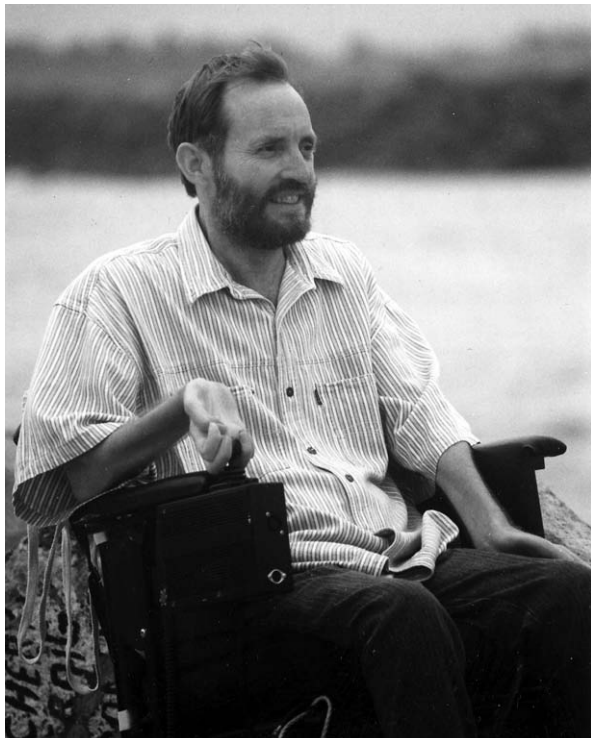
*In the Spinal Unit 1982.
Don spent seven months there recovering
enough for us to come home and
start our new lives.*



*Don and I at our home in Lake Road, Port
Macquarie about 1987. This was a really
good time for us all. Although quadriplegic,
Don's health was reasonable.*



The family in about 1988. We had so much fun together and the girls remember most fondly the stirring that went on between them and their dad – they remember it with love and have told me this.



Don at the Breakwall, Port Macquarie about 1990.



Don with his sister Judy (died 1998) and his mother Kath (died 1997), pictured 1995.



Don at Shelly Beach, Port Macquarie NSW in 2001.



Melissa, Don and Alison at Oxley Beach, Port Macquarie NSW in 2000.



Admission to the Sydney Hospital

Don's transfer to Sydney by air ambulance was not as the result of a medical emergency. I had been looking after him at home, without any professional medical care at all, until the day he went to hospital for transfer to Sydney. We believed that the only way he could travel comfortably was by air, due to his severe osteoporosis and other conditions.

It is only recently that I learned from Melbourne medical specialist Dr John Marx that people with brain injury or fluid in the lungs should not be transported by air. The sudden changes in air pressure, from the unpressurised planes especially, affects the brain fluid and lung fluid, and can be life threatening. It is very important.

On the day Don was flown to Sydney, he had been in hospital all day, awaiting transfer. By the time they came to take him to the airport, he was already very tired. We'd been expecting the plane all day but it didn't leave until evening. We left the local hospital for the airport at 8pm on a mid-autumn night, with no special in-flight care to be provided apart from the attendance of an air ambulance nurse. For a quadriplegic to be transferred like this was quite an ordeal. Once out of his wheelchair, Don's nursing needs intensified. But still there was no crisis and no drama. As far as we were concerned he was just travelling to Sydney to have his right lung drained and a biopsy performed to ensure there was nothing serious causing the fluid build-up, such as cancer.

Don told me about an incident which occurred in our local hospital, just before leaving for Sydney. When I read his nurse's version, I could only shake my head. Don had asked the nurse to put some mouth moisturiser on his knuckle (his fingers didn't work) so he could put it into his dry mouth. Mistakenly, she used a gel (Voltaren) rubbed into the skin to numb pain rather than moisturiser. To cover her mistake she wrote, "The patient then put it into his own mouth," but that never explained why she would have used the gel at all. Don didn't need it on his hands. And this gel should never be put in anyone's mouth. The worst things can be justified by shifting blame or pretending something wasn't seen or just didn't happen.

As Don was being lifted from his hospital bed to the ambulance trolley, a large wart he'd had on his chest for decades was ripped off, and bled onto his clean white T-shirt.

I said to his nurse, "What's happened here? He's bleeding." I pointed out the spreading bloodstain to the nurses and lifters, but they ignored it. The nurse said, "It's just an old stain", but the obvious fact that it was spreading gave a lie to that claim. I made them stop, lift up his shirt and at least cover the open wound with a bandage. The wart was missing and the wound was bleeding. Rather grudgingly, the nurses put on a gauze pad, held with tape. The last thing Don needed was to be heading into the hotbed of infection that this particular Sydney hospital was infamous for with an open and bleeding wound. But we didn't cause too much fuss about this wound incident. By this time, we just wanted to get the transfer over

with. We were both worn out. But it was another sign of the attitude of too many nurses where, if they pretend not to see something, it doesn't exist.

The incident was not noted in hospital notes, even though I believe it is a compulsory requirement for all medical staff to note in medical records any matter or incident affecting patients.

I remember holding Don's eyes at this time. He gave me the cross-eyed look at the hospital shenanigans and we shared the joke silently. If I had known how many weeks we would have to spend with just his eyes for communication, I think I would have wheeled Don out of hospital to our van and left – and taken our chances. But instead I drove to the airport in our VW van behind the ambulance. I made sure that the ambulance nurse had Don's medication close by in case his blood pressure skyrocketed. I stressed that Don would tell her if he needed it and to please listen to him. I laboured the point, because too many nurses previously had claimed to know what this condition was all about, but then showed they didn't when it needed treating as an emergency. But the air ambulance nurse was excellent and I could tell he'd be fine with her.

I later met this wonderful nurse here at my home. I had been talking with her on the phone about that night back in 2007 which she remembered in detail. We discussed what time she left Don at RNSH. She brought the flight record around to my house and when she saw me she just held her arms out and gave me a big hug. I broke down and cried at this unexpected kindness from a stranger. She had treated Don with great dignity and was upset at the outcome. Her name was Kathryn Sheppard and sadly she was the Wingaways Air Ambulance nurse who was killed along with the pilot in the aeroplane crash at Canley Vale June 2010. One of the good people and one I will never forget.

It was cold out at the airport and Don was lying there on a stretcher waiting for the plane, still in the ambulance. He had his woollen beanie on and was smiling to the nurse and me. From past experience he and I knew we were going into the lion's den – but we just talked quietly. I touched his arm and head a few times to communicate in our way and just be reassuring. I wanted to hang onto him, I remember clearly feeling this. The plane landed and taxied over. I stayed near Don as long as I could.

I said: "I'd like to drive down to Sydney tonight behind you."

Don got upset with me and said: "No way. You'll end up under a semi-trailer. Have a good night's sleep and drive down first thing tomorrow and I'll see you then, OK?"

I said my usual: "See ya round like a rissole." He usually answered: "Eh! Eh!" because we were long time Aunty Jack fans from the mid 1970s and this was a daily greeting. This time he just said: "See you tomorrow, Spider" – that being a pet name he had for me. God, I wish I had thrown his air mattress out of the plane and just flown down with him. But how could I know what was going to happen? All I knew was that he needed the air mattress so he didn't end up with pressure sores from the slapdash nursing care he was likely to get. Because of that and needing to bring down his wheelchair and other equipment, there was no room for me and we understood this.

After I watched Don's plane take off safely I returned home. It was odd to be in the house by myself, a bit freaky because it almost never happened. Friends had picked up our old dog Thorn, so the house was totally empty and really quiet. Left alone with my thoughts, I remember feeling as if I was stepping into an abyss. It always felt like this if Don had to go into hospital. Things that we felt we had control over, like his life and our future, were taken out of our control and often it took a lot of time and effort to get our lives back when we did get back home.

I didn't get to bed that night until about 2am. Even thinking we'd only be away a few days, there was still so much to organise. I assumed I had to pack and prepare for a week but I also knew it could turn out to be a fortnight. So I packed heavy and took all the financial things with me that I'd need to deal with.

It was now 11 April. Don had spent a lot of time getting organised for Melissa's wedding to Chris, scheduled for 19 May. Chris's family originated from Kalamata (famous for its olives) in Greece. The cultural history was very strong with them and so Don, as was his wont, decided to ensure that his own Scots-Australian heritage also put in a good showing at the wedding. He organised a Mackay tartan outfit; an Australian-Scot, Steve Walker, to be the Master of Ceremonies; a Haggis Ceremony; and a young local bagpiper to play at the wedding. He wanted us both to accompany Melissa down the aisle, being piped in by the bagpiper. I just sat back amused as all this went back and forth between Don and all those involved in the planning. He wanted so much to be at that wedding.

I left the house the morning of 12 April 2007. I can recall exactly what I saw and heard as I left, even down to the sound of the front door shutting. It was a sunny autumn day. In those days the front gate was never closed and I idled the van down the long driveway as quietly as I could, not because of neighbours – there are none close by as we live in a rural setting – but because I just felt like that moment of quiet. The tyres crunched the road surface, and three magpies were already about on the ground searching for breakfast. I knew once I turned out on to the highway I'd be part of what was happening, having to concentrate on the road and keep up to speed. Like Don, I was very reluctant to return to the Sydney hospital.

I could never have dreamt that when I saw him later that day, the dye would be cast and the damage already done. By then he'd had the operation, and unbeknown to either of us, had no real chance of survival. I drove down to Sydney and arrived about 1.30pm. I felt such a sense of relief when I walked into the ward and there was Don smiling back at me from the bed. I realised only slowly that the surgery had already been performed.

The Operation

Dr H. – Director Clinical Governance – of the Sydney hospital wrote in his letter dated 2 January 2008. “The very rapid progression from admission to operation meant that there was no assessment by the Spinal Unit or with the respiratory Unit preoperatively. I recognise that given the complexity of Mr Mackay’s condition, a more comprehensive assessment, with input from the spinal and respiratory teams prior to surgery, would have been wise.”

When I originally wrote up my memories of the first days in the Sydney hospital, there was a lot I didn’t know. Although I had the hospital records, they were so badly written I couldn’t follow what they said. So much was indecipherable. What happened to Don inside that place was so bizarre as to require a full independent investigation. Too many threads so totally bound him that it’s hard to untangle them. I know today that there are people still working in there who know more than I do. They know what happened to Don. Some are directly responsible. Others helped them evade censure and correction by covering up what happened. Many people in medicine accept such things as part of the culture.



According to the notes, Don was admitted to Ward 7D in the Spinal Unit at 9.45pm, and by 10.45pm had signed the consent form for a “right-sided video-assisted thoracoscopic pleural biopsy, chest drain, pleurodesis and thoracotomy.” A thoracoscope is a narrow tube with a viewing mirror or camera, which is used for viewing the chest cavity; a thoracotomy is a cut made in the chest wall.

Knowing as I do what it would take to unload Don from the ambulance trolley, make him comfortable in bed and administer all his medication, the claim of one hour for this entire sequence of events is not credible. It could not have happened within that one hectic hour. In the hospital notes it says that Don’s skin was in good condition and he was alert, something that was later ignored.

I accept that Don signed this consent form. Yet why can’t the interviewing specialist, who obtained the consent, remember what he told Don about what Pleurodesis could mean to him? Did this doctor explain there was a high probability it could kill him in his weakened condition? How was Don able to read the whole consent form while lying down? Someone would have to find his glasses and stand there holding the form to ensure Don could read it, or else read out every word to him. I doubt this happened. How could Don have had the time to absorb all the possible side effects of pleurodesis and then make a fully informed decision? It was not possible in the space of that first busy hour, if done properly.

Melissa, Alison and I can guarantee that had Don been fully informed of the very real risks to him of Pleurodesis, he would never have signed the consent form. Don and I were never told about this procedure by his doctor or by the local hospital. We didn't even know what it was. We both left the local hospital thinking he was being flown down to have his right lung drained over some days, have biopsies taken and then, if the biopsies showed nothing much, go home. How could the local hospital's discharge notes state "Pleurodesis" on his discharge notes when Don had not even been seen by a cardiothoracic specialist? How can things be so sloppily done by medically educated people?

Don was scared, almost to the point of paranoia, of any surgery. Some years before when he had to have bowel surgery, his eyes were on stalks. Over and over he asked that the hospital make sure his specialist did the surgery and not some trainee. On this he was unyielding. And he had every right to be scared because, as a quadriplegic, any surgery and anaesthetic was deadly serious. All quadriplegics know the grave dangers of any interference with their lungs. Many choose not to even have flu injections, although this makes their doctors jump about the place. What too many doctors don't understand is that quadriplegics can't afford even the mild dose of flu many get from the injection itself. It is a serious risk for them. Don would never have the flu injection. I supported him fully in this and have never had one myself. In the winter months we just kept away from crowds. For almost 25 years, his lungs were clear and not much problem at all. It worked for us.

If doctors in Sydney had told him they were just going to do a lung drain and biopsies, as Don expected, he would of course have signed. He was desperate to be treated and get back home. Melissa's wedding was on his mind and he wanted to be better for it. Had he heard mention of the word "Pleurodesis" however, the only way he would have signed would be if the doctor glossed over the side effects and presented this procedure in the same light as the lung drain: "Just a simple procedure with almost no risks". Don would never have signed for that surgery had the interviewing specialist told him that should it fail there was a real risk of Acute Respiratory Distress Syndrome (ARDS) developing – as indeed happened. He would never have consented had they told him that if the Pleurodesis failed – as it did – the damage to his lungs would be life-threatening.

I lived with Don for 35 years. With few exceptions we were always together. Sometimes it seemed we knew each other too well, which has its ups and downs. It appears that my husband Don did not give informed consent to a Pleurodesis as there was not time for the explanation of the full risks to him to be explained. Everyone is entitled to have the risks of any medical procedure fully explained, but it is even more essential for someone with the complex medical problems Don had. The interviewing specialist who first saw Don must have – or should have, at least – understood his frailty, his very limited respiratory reserves. He had a duty of care to step back and ensure that a full, comprehensive care plan was in force before any surgery was done. This did not happen.

Don did not even need a Pleurodesis, which is normally performed only in cases of recurrent pleural effusion, because Don had never had a recurrent pleural effusion. The effusion was only discovered in late February, and had only

ever been partly drained. But even a recurrent pleural effusion, if moderate, should have been treated conservatively, particularly in Don's case. Pleurodesis was way too dangerous for a quadriplegic with limited respiratory reserves.

The interviewing specialist later claimed he could not recollect what he told Don about Pleurodesis, but that in itself is deeply unsatisfactory. There should be a set and mandatory explanation for patients of surgical procedures such as Pleurodesis, stating all the risks and side effects including the danger of ARDS. Every patient should be fully informed and told the same things, but as well, because of Don's quadriplegia and his marginal respiratory reserves, the real risk of ARDS should have been explained to him. Yet there is no record of what information Don was given before signing the consent form. The senior surgeon who performed the procedure was the admitting specialist, who said later he "assumed" Don had full knowledge of the Pleurodesis prior to his transfer to Sydney – but on what was this assumption based?

In common with most people, Don and I had never heard the word "Pleurodesis", so we would not have been in a position at that time to query its suitability. But whether or not Don understood the true risks to him is beside the point anyway. The central point is that this operation should never have been done on a man in Don's condition in the first place. He was a quadriplegic with limited respiratory reserves; was unable to fully expand his lungs; had fluid in his lung; and was having biopsies taken. Taking all these things into consideration, to have talc inserted into the pleural lining at the same time was a risk that should never have been taken, as he was unlikely to survive it. A doctor who held a duty of care would have accepted this and gone for the conservative option.

Since Don's death, the authorities have gone to great lengths to push the view that Pleurodesis is the required, standard treatment for all those patients with fluid in the pleural lining. On the contrary, however, I now know that the usual and more conservative treatment, at least initially, is a lung drain and biopsy to determine the cause of fluid build up.

A doctor who had been my husband's spinal specialist in Sydney for some time told me after Don died she thought he was being transferred to the Sydney hospital for a lung drain and biopsy. She was away for the month he was there, from my understanding. After his death, she expressed shock to hear he had had a Pleurodesis. She told me that even if the fluid had built up again – i.e. if it had been "recurrent" – it would have been easy enough to just drain the lung again, since it was a very slow build up. Considering Don's state of health and the dangers of interfering with his lungs because of quadriplegia, she was very certain that only a lung drain and biopsy should have been done. When I left a message after Don's death, she rang back and told me she had thought he would have been "home and well" by then. Pleurodesis was not only unnecessary, it was considered by this doctor to be potentially dangerous.

Apart from anything else, the haste to carry out this operation was bizarre. There was no emergency. But following all the inquiries after Don's death, I have had no further contact with his spinal specialists, which is a shame. There is a lot to be learnt from what happened to Don.

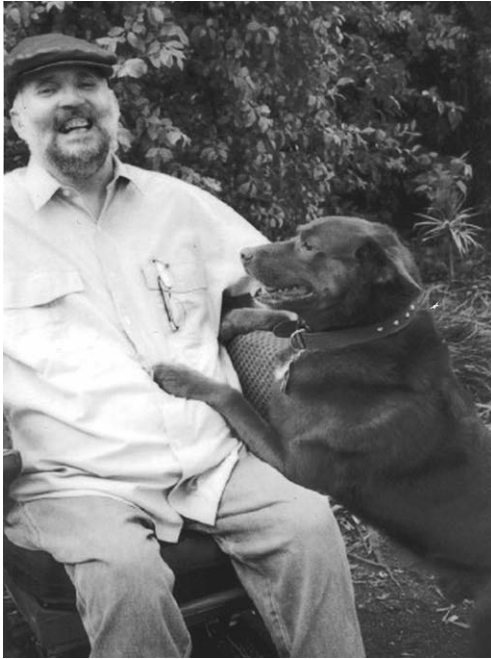
In the ambulance at the airport was the last time I was to see Don when he had any real hope of survival... and it is hard to bear. It wasn't that he was going towards an unavoidable, unforeseeable accident; it was as if the main pieces of a macabre chess game were moving unknowingly into the place set for him.



When I arrived in the ward in the early afternoon of 12 April 2007, the operation was already over and Don was sitting up in bed, wide-eyed and very aware. His big surprise for me was that it was all over, all done, and no doubt we'd be home next weekend in plenty of time for Melissa's wedding. He was cheerful and happy that afternoon and fully recovered from the anaesthetic. It was the very best recovery from anaesthetic I'd ever seen him have. I was so optimistic that afternoon. I didn't query informed consent and Don didn't speak about it because we both assumed his surgery had been similar to the partial lung drain at our local base hospital. We thought we'd be home in days. He and I had no idea what had been done to him in surgery.

The next morning – Friday the 13th – the admitting specialist and head surgeon during the lung drain, biopsy and Pleurodesis, seemed very pleased with himself. He told us: "We put slurry (a watery mixture) of talcum powder into the pleural lining and there will be no more fluid build up." This meant nothing to either Don or me. The doctor never once mentioned possible adverse reactions. That was how Pleurodesis was explained to us.

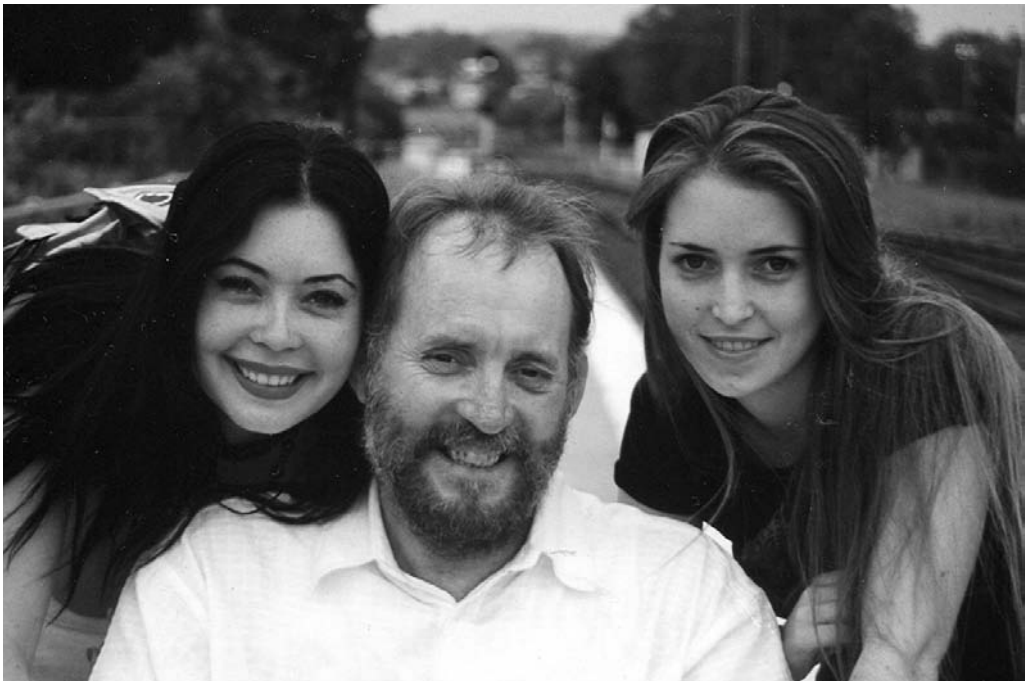
Near the end of the day, I noticed some of the things Don was saying seemed a little odd and out of place. It had been a gruelling time for both of us, so I wasn't overly concerned, but thought I should just mention my observations to a nurse. Along with the many concerns I voiced over the coming days and weeks, this was not recorded.



Don and Alison's wonderful kelpie, Thorn. He was so gentle with Don and gave him much pleasure when he lived with us. Sadly this dog died one year after Don, he was exceptional.



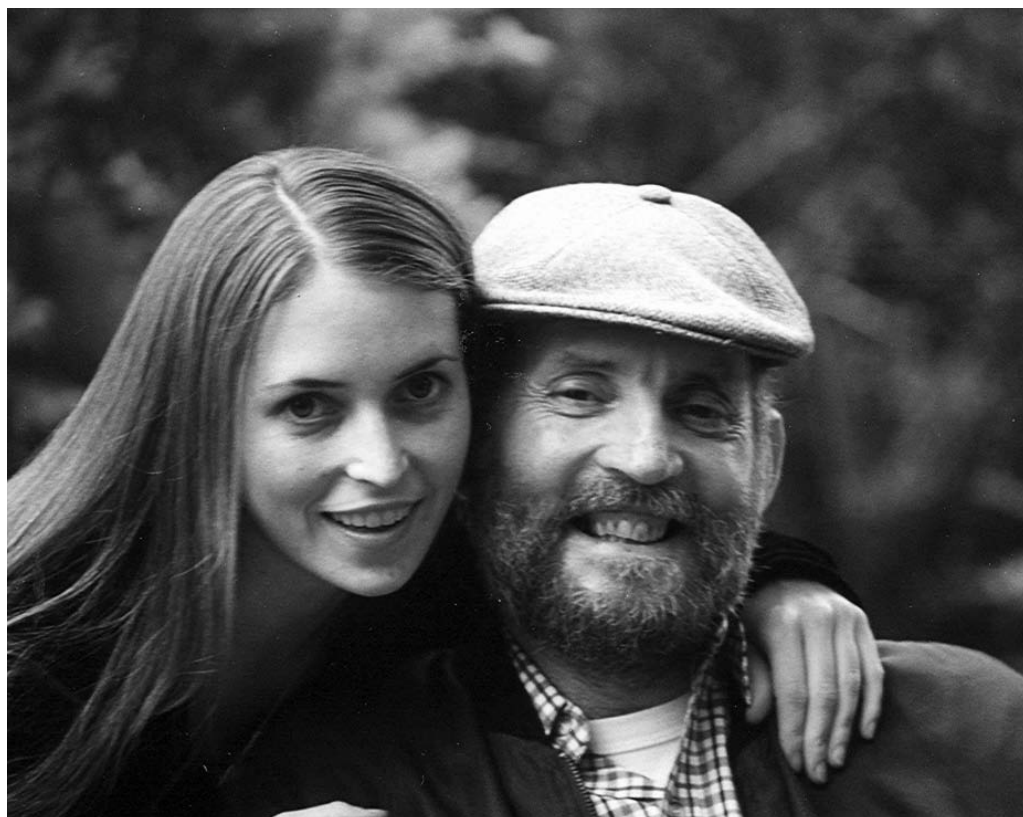
Don in 2004.



Melissa, Don and Alison saying goodbye at Wauchope Railway Station, NSW.



Don and I.



Alison and Don – so many wonderful photos of him and his daughters.



*Don and I at the Bago Winery.
He rarely drank but was clearly enjoying
himself here.*



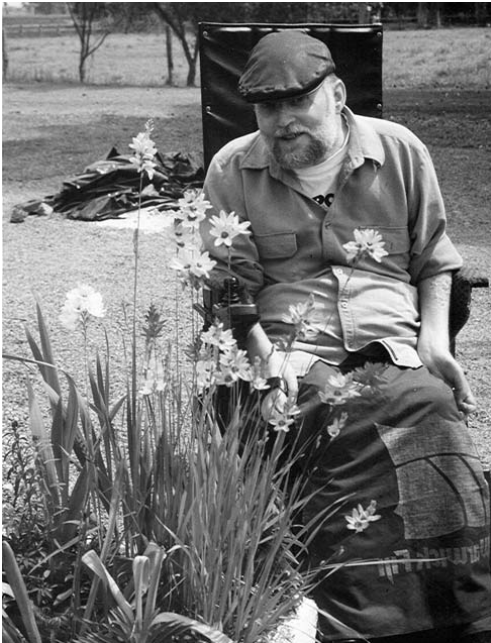
*Don once again with his hat, he was
seldom without this, it was like an
essential item of clothing.*



*Our 2005 Christmas in our new home at Craggy Island. It was a wonderful day
and we were all in the Christmas spirit.*



The years pass – grey in the beard. Don and I in 2005. We were pretty happy little vegemites even though he suffered extreme pain at this stage.



Don at our new home with his gift from Alison of flowers – he loved the garden and everywhere we lived was made much more beautiful through Don's love of the natural world.



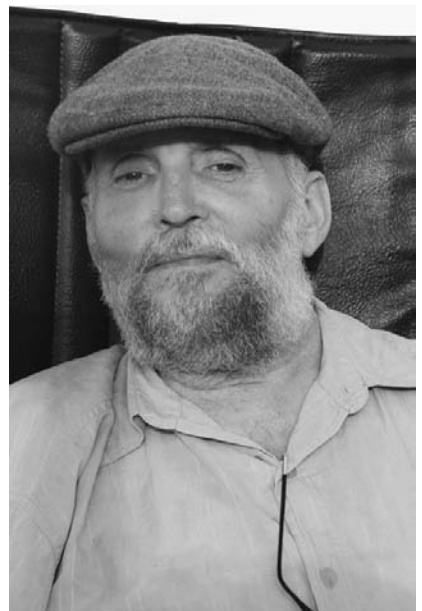
Don in 2006, just before the breathing difficulties.



Melissa and Don – the love is visible between these two – Don was the best father our girls could have ever wanted.



Don and I in 2005, he was suffering on this day but never complained although my family were present. I could always tell the level of pain by how he sat in the wheelchair. In this photo he is sitting crooked trying to ease the pressure and therefore pain on his hip joints.



A favourite photo of Don, he was struggling a little with his breathing by late 2006.



Don loved to be in the centre of women and was here, with my sisters Joan and Veronica, and smiling fit to burst.



The girls and Don on our last Christmas Day 2006. I think he knew he might not have too many more Christmases and he went all out to show his love to us all.



Don and Melissa Boxing Day, 2006.



Don and Alison Boxing Day, 2006.



*Our last family photo – taken Boxing Day 2006. Here he is tucked in between us all.
How I wish our love and protection could have held him as safely
in the future as he was here in this photograph.*



*Melissa, Don and I in March 2007.
Don was visibly fragile and weakened –
not noted by doctors how serious his
condition had become.*



*Early April 2007.
At this time Don and I were so afraid
that at any time he could die – his lack
of care medically had left him weak
and struggling – something the
city doctors ignored.*

CHAPTER 8

A Catalogue of Errors

What I now know from research but mainly from Dr H's internal hospital Report is that there was no assessment of Don before surgery. Not one. I find this unbelievable but it is true. It wasn't to be until around Christmas, seven months after Don's death that we found out just how many mistakes they made. Even when I was a child in the mid-1960s having my tonsils out, I was aware they followed more procedures than that major teaching hospital's cardiothoracic team in 2007.

I list here just some of the areas where that hospital fell short in Don's treatment.

- In a 2002 article in *Chest Journal*, Dr Richard Light, MD, FCCP, Director of the Pulmonary Disease Program, Saint Thomas Hospital in Nashville, Tennessee, stated that talc should not be used in Pleurodesis because of the high incidence of ARDS occurring in patients after its use. He wrote: 'What is the future for talc as a Pleurodesis agent? Talc is basically dirt. It appears to me that in the year 2002, we should be able to find an agent that is more specific for the induction of Pleurodesis than dirt!!'
<http://www.chestjournal.org/cgi/content/full/122/5/1506>
- It is accepted as bad medical practice to do a Pleurodesis at the same time as a biopsy; this is a course of action contraindicated in many current studies and the admitting specialist and team should have been aware of this, especially when dealing with such a debilitated man as Don had become. Don was also given the highest dose of talc. In the handwritten notes done at the time of the surgery they write that 10 grams of talc were sprayed into the pleural lining. Later on in the typewritten notes, this was changed to 7 grams. The hospital authorities have never adequately explained this discrepancy and the question has to be asked, why was this changed?
- Furthermore, ungraded talc was used. This is not recommended as best practice. It is linked with inflammatory response, which is exactly what happened to Don. The hospital admitted this problem when we brought it to their attention after Don's death, and have now said they will no longer use ungraded talc.
- Pleurodesis should never be done on someone who cannot fully expand his lungs. Don had been unable to fully expand his lungs since 1982.
- Pleurodesis should not be done while there is any fluid still present. Don still had fluid in his lungs at the time of surgery and it was still draining after the surgery.
- If the admitting specialist and his team had observed their duty of care towards my husband, they would have seen from the local hospital notes that the physiotherapist had done a Spirometry on Don which showed the very real breathing problems he was having, including her statement that Don had 'a lung age of over 100 years'. They should have stopped and waited and

acted conservatively, and it still puzzles me to this day why they went ahead in the rushed manner they did. They should have done their own testing, especially considering there would have been changes in the fluid in his lungs from air pressure changes caused by the flight in the air ambulance. Given his quadriplegia and marginal respiratory reserves, Don was already debilitated, even before the unnecessary and dangerous surgery done soon after he arrived and while I was still driving down Sydney.

- The admitting specialist was according to Dr H. the chief surgeon. He saw no X-rays or scans prior to surgery, because they were still in the local hospital. How could a medical professional go into a quadriplegic's lungs without knowing exactly what was going on there? Nothing I have read or been told makes any sense of this. He had not seen Don before theatre and had not done a detailed examination. The person who signed him up the night before was not part of the surgical team. No one knew anything about his multiple conditions before surgery.
- There was no ECG prior to surgery although Don had been diagnosed a year before with a small pericardial effusion, or fluid round the heart – in itself, a contraindication to the surgery. There were no blood tests, nor any pathology. How could this happen? Don was a quadriplegic but they went into his lungs minus any ECG which should have been done before the surgery. I have looked at Don's ECG results from after surgery, and most mention 'abnormal ECG.'
- The Sydney hospital admits that the admitting specialist and chief surgeon 'assumed' Don had been examined by a cardiothoracic specialist in locally. Yet all he had to do was cast his eyes down the discharge notes to see that the only contact Don had with a cardiothoracic person was a phone call between the replacement doctor the third to see Don in a week or so back in March, who had no knowledge about quadriplegia and lungs, and a doctor from another town who never saw Don, and who therefore had no idea about his real condition.
- The pre-operative review by the anaesthetist is admitted by the Sydney hospital to be 'limited', despite the fact that the complicated medical problems Don had required proper assessment. After arrival at there, there is no evidence in the notes that Don was seen by anybody other than the interviewing specialist, a cardiothoracic registrar, and the night intern from Spinal. As far as we know, Don was not reviewed pre-operatively by an anaesthetist, an anaesthetic registrar, or the admitting specialist; nor by a surgical registrar, or a spinal or respiratory registrar.

The Health Care Complaints Commission, after being made aware of these facts, said all of the above and all to follow was 'acceptable'. Yet for specialist doctors to just go into Don's lungs in the way they did, considering all of the above seems to me to imply a considerable depth of medical ignorance in failing to inform themselves of the parameters of Don's condition. No one has yet explained to us why the surgeon, the admitting specialist, acted like this.

It is the weirdest thing; when I try to recall the admitting specialist's face, he has none. Even though I know I only met him twice, I can't understand this memory blank. It's like someone put a big smudge mark on his face. A lot of the people I met in the five weeks of that time have that same blurry face in my mind. Name tags would have helped. Supermarket staff wear nametags. Bank tellers wear nametags. How much more important that those who deal with life and death wear identification? For some I met there, I can remember hair colour, voices, accents, even the walk. It's got me beat, this blur on the faces.

There is an anaesthetic and recovery room record that has been completed by the anaesthetist. He has not made any record in the progress notes on the ward pre-operatively; it may be presumed that he made his assessment of Don in the anaesthetic room immediately prior to surgery. The anaesthetic record shows he ordered a pre-med of Adalat, for autonomic Dysreflexia. The notes also appear to show that the doctor administered and signed for the drug.

There is no record of a pre-med being ordered on Don's regular medication chart. There is a special area on the chart for pre-meds which are given once only, prior to surgery, by the ward nurses; the first record of a once-only drug is dated 13 April 2007. I could make an assumption, therefore, that Don was not visited on the ward by an anaesthetist or anaesthetic registrar. The Sydney hospital's investigative report – known as a Root Cause Analysis (RCA) – implies Don was first seen by the anaesthetist in the operating room. The RCA report acknowledges the pre-operative assessment was rushed. In a letter to me, Dr H. also notes that "there was no time to develop a comprehensive care plan which involved yourself and spinal and respiratory medicine." Furthermore, he "regrets you were not involved in the consent process".

Now this issue worries me and it does not make any sense. In Theatre it is noted that they asked Don at 8am various questions and have noted that he answered. But later when at 9.45am where the question of patient involvement is listed, it is noted that Don was now asleep and could not answer, or did not. Who can tell with these notes? I don't know whether he was already unconscious, or not, but on the form there is a place marked "Patient Involvement" and one would assume Don was meant to be able to answer here. It's a minor thing, but is of concern. I can state here without any doubt at all that unless Don was totally knocked out he would have been wide awake. Surgery terrified him, and with good reason as it turned out.

But there was time. There was plenty of time. The hospital authorities have never explained to me the peculiar view that there was no time to waste. Don had travelled down to Sydney in an air ambulance without any medical incidents. The hospital, and then the HCCC, tried to generate a state of emergency in Don's treatment. I only found out, in April 2009, that he was not even transported by the ordinary air ambulance, as we had thought, but by the privately owned Wingaways air ambulance which is used, as they say themselves, "*for transporting non-urgent patients.*" There was no urgency, no emergency.

A good doctor with a care for his patient would have trodden very carefully with such a patient as Don. The fluid he had in his pleural lining had not increased, according to the local hospital's notes, since an earlier reading ten

days before. We coped at home with this situation, minus oxygen and medical help. Yet within hours of their having the care of Don, they performed a hasty, rushed procedure he had almost no chance of surviving, which led to his death five dreadful weeks later. But their evidence is accepted by the HCCC and others as professional, and given credence.

The notes in my possession show that the interviewing specialist recorded Don's Spirometry result as "normal", when in fact the Spirometry had shown severe restriction of all perimeters, consistent with C5/C6 quadriplegia and a patient with a moderate pleural effusion. This is surely something to be questioned further.

Most concerning is that Don's condition was a complicated one, and fairly major surgery was to be performed on a patient who obviously had an increased risk for complications because of his quadriplegia and limited respiratory reserves. He also was on a variety of medications which should have been of particular interest to an anaesthetist. Furthermore, performing chest surgery on a C5/C6 quadriplegic has particular risks that should be assessed prior to surgery. It would have been prudent for the medical attendants to discuss this with the patient and his relatives. As we are all too well aware, this did not happen.

Pre-operative assessment by a spinal specialist and by the attending cardiothoracic surgeon or his registrar was obviously indicated, as clearly there was an increased risk for surgery in a C5 quadriplegic patient. As is shown by the clinical notes, there was no such pre-op assessment.

Why, with all of the above markers, would any specialist surgeon do surgery without at the very least having examined a chest X-ray prior to surgery? As no X-rays were taken pre-operatively in Sydney, and as the X-rays from the local hospital did not accompany Don in the ambulance, it can only be concluded that the surgical team did not have the benefit of any X-rays prior to performing surgery. This needs to be questioned. The first X-ray done on Don was when he was in theatre after surgery. The hospital's Root Cause Analysis, received months after Don's death, also acknowledged the maximum dose recommended for talc had been exceeded, and acknowledged the need to change the talc used to a graded quality.

I wish I could understand all the notes. I have tried, and I even hired a medical person to look them over and do a report. That report raised some issues, but was incomplete in many areas. There was just too much to take in. Along with solicitor's fees, I just couldn't afford to hire any more professionals. Most of the time, the family has done as well as the experts anyway in piecing together what happened, and what went wrong. But I missed a very important point which, if the internal hospital report had not inadvertently drawn it to our attention, we would never have known about.

In theatre, it is recorded that one of the doctors wrote instructions that Don's right lung was to be left on suction back in the ward. It should have been suctioned until all the fluid was removed at the gentle suction of "3 KPA". However, this doctor's handwriting was so bad that it was read in theatre and on the ward as "31 KPA". Don's fragile quadriplegic lung was suctioned at a rate ten times higher than it should have been, for 22 hours! Neither Don's admitting specialist, who

should have told us, nor any of the team in the five weeks that followed, mentioned this serious mistake after surgery. It was buried.

I have read the convoluted reasons the hospital gave in trying to explain this blunder away. If I wasn't confused when I began, I certainly was at the end of this bit of obfuscation. They admit that a "transcription error" caused Don's lung to be suctioned at ten times the correct value, and that the wrong rate was not spotted by cardiothoracic doctors and Spinal Unit nurses until 8am the next day.

Don was an ailing quadriplegic, and lung problems are among the worst things that can happen to any quad. After his accident in 1982, we were advised that if Don developed even a slight chest infection, we should go straight to hospital as it could easily and quickly turn into pneumonia, given his inability to cough. And yet what did they do, having suctioned Don's lung at ten times the correct rate and after doing a dangerous procedure on him? They put him on six-hourly observations – meaning observations were required only once every six hours. These "observations" fill only one A4 sheet of paper on one side and one entry on the other. Called a "flow chart", here a patient's blood pressure, temperature and pulse rate are recorded. When I requested Don's hospital notes, this very significant sheet was left out and I had to ask for it again. Such observations were woefully inadequate for a quadriplegic patient with such a potentially dangerous problem developing in his lungs.

When the suction mistake was finally noticed, what they should have done was increase their watch on Don, note his responses closely and tell us. When I drew this issue to the attention of the Coroner's office, it was this very issue which caused the Coroner to reopen Don's file.

To put a high-level quadriplegic patient on six-hourly observations was extremely negligent treatment, even if there weren't other issues. Whenever Don was bedridden at home – with no lung suctioning complication or any major illness – I would take his blood pressure on demand to monitor his autonomic Dysreflexia, seldom be out of sight or earshot in case he needed help, and constantly checked on him. He was totally helpless once in bed, and his condition could alter quickly due to daily bouts of Autonomic Dysreflexia. One time, when he spent six months bedridden, I'd hang the washing out on the verandah as I was not game to go even the short distance to the clothes line. We paid someone who knew what to do to be with him so I could make twice-weekly trips into town for groceries and banking. That's how we lived, and it was well worth it. Don and I were always happiest together, or when the girls came home and the four of us closed the doors on the world. In hindsight, maybe with good cause.

For the Spinal Unit nurses caring for Don, observations should have included temperature, blood pressure and pulse, as well as checking his lung drain, urine bag and colostomy bag. As he was visibly breathless, they should have checked his oxygen levels frequently and reported any signs of trouble to doctors because of the lung surgery and quadriplegia. He was an "At Risk" patient. Any problem Don complained about or that I raised should have been recorded, but the Spinal Unit nurses recorded nothing, so their observation charts do not reflect reality. Their observations were only of the equipment around the patient, not of the person. This was the crux of the failures.

The cardiothoracic team must have suspected that some damage could have been caused to Don's fragile lungs by the excessive suctioning, and common sense would warrant close monitoring. Yet they actually ordered a lessening of observations after it became clear he was getting worse, as evidenced by night time episodes Don began having. His oxygen saturation levels were fluctuating and the night intern recorded he was "muttering and disorientated." I was not told about this at the time either.

It is the responsibility of the surgeon to see that all procedures pre and post-surgery are followed. Almost none of the regular procedures were followed. There is no excuse for this.

Some spinal nurses, doctors and members of the cardiothoracic team were habitually careless or irresponsible over the next days. Don was treated badly as his condition became dangerous. When he began to hallucinate and gasp for breath, he was ignored. This was extreme cruelty and shocking for him to experience.

In writing the above about my care for my husband, it might be assumed by those with little knowledge of severe disability and the nature of life affected by it that care is an onerous responsibility. In our case it was literally full-time care – 24 hours a day, seven days a week, with little respite for over two and a half decades. A hard task, I don't deny. But I am no martyr; far from it.

I never felt that way. Where else did I want to be? Don and I had the richest life together, with much love and warmth between us. I always felt I was the luckiest person on the planet because of our love. Not everyone experiences that.

Our house rang with laughter, and our girls can give evidence to this, not that this is necessary. Our lives were the richer because we knew how precious each day together was, and that's how we lived.

Many in our position are the same. Many outside our experience have trouble understanding the nature of relationships such as ours.

Most of the time we both woke up fresh at the beginning of the day, as I said in a poem I wrote to him a few years before he died. Lucky that I read it to him and gave it to him and that he knew how I felt. I got to tell him properly. Too many miss out on doing this.



The Man and Me

Sleeping at night my palm opened flat on his chest,
Warmth feeding warmth, I know we are blessed.
No matter the day's misunderstandings and blues;
No matter points made and lost;
No matter who thinks who's the boss;
Sleeping always next to him is the life I would choose.

Re-arranging pillows, blankets and such;
Both easy to fire off, yet both easy to touch.
Each unwilling to give way, equal to the end.
The Celt in us both, a marvellous brew,
Stirred and stirring, a wondrous stew.
Sleeping hand to chest our rousing battles mend.

Ah! And give me that fire, pure and unpolished,
And give me the spirit, no argument undemolished,
And give me the wickedness and its play,
Give me the empathy and knowing
Give me the common sense for our growing.
And let us wake hand to chest at the start of the day.

How dear to me is the man who breathes beside me at night?
How dear is the spirit, which gives his eyes their light?
How dear to me is the world we share?
There is no measure I can explain
But that his pain gives me also pain
And that our love is sometimes more than we can bear.

For me he stands, young, fair and clear-eyed as in youth.
For me, the things he feels I know, they are truth.
And I will hold these truths like rare and precious treasure,
For in a shifting sea of easy useless lies
The values of such truths are cherished ties
To the love which lives within the heart which is without measure.

So let me lie for hours, my hand upon his chest,
Thinking on the treasures with which we are blessed.
Such as our children treading out into the world to be,
Carrying the dreams of all our life;
Treasures as sacred as the man and wife
And as sacred as the love which binds the man to me.

That's how we were.

I sensed something might be a bit wrong the afternoon after the surgery, because near the end of this day I noticed slight things which concerned me about my husband. Just the odd things he said which seemed out of place. Not much. A few sentences came out in an unconnected way, as if he was just very tired. It had been a torrid time and we were both flat. I did mention a concern to a nurse but this is not recorded, as none of my many and growing concerns would be in the coming days. The nursing notes here are of interest because even after the long day he'd had on 12 April, Don is described as 'alert and orientated'. Any later deviation from this should have rung loud alarm bells.

Don had returned to the ward at 12.30pm on 12 April, after the Pleurodesis operation; the next notes from nursing staff are at 3.25pm. A long time between observations, unless I don't have all the notes and obs. were made somewhere else. The times between nursing notes in the Spinal ward were stunning. They have him taking Tramadol, a painkiller. Why is this? He hadn't taken this drug for years. There was a serious incident with his afternoon medications, either this day or the next. Don had some medications for bladder and other issues, but he was also on Physeptone and Neurontin for pain. When the nurse tried to give him his meds, I asked her where the rest of them were. She looked at me and said, "This is all he takes." We had a look at them and noticed that the Physeptone and Neurontin were missing, amongst others. We pointed out to her the list of his medications we had brought from home, for just this event, which I had stuck up on the wall near the bed. I found a senior nurse. Then they got out the notes they had for him. They pointed to the meds sheet, where it was clear the most important medications were not listed. I looked at the sheet and turned the page and there they were. Don would have developed serious withdrawal symptoms if I hadn't pointed this out, and no one would have been accountable because no one made a note of this slip-up.

Many hospital staff are too often too quick to be adversarial, rather than to use common sense and figure that a patient's family might actually know best.

The notes mention right upper arm pain. That arm remained painful after the operation, and misshapen. Melissa and Alison noticed a strange 'lump' from the time of the operation until when Don died. His arms and legs were so wasted by quadriplegia that anything like this stood out. This, like so many things, was never really looked into. I knew every inch, every lump and bump on Don's body, and something had occurred which caused him pain. Running your fingers over the top outside of his upper arm you could feel a bump, as hard as bone. We argued the toss with them, Don and I and they X-rayed it. We were told it was nothing but referred pain, which was partly true, but something quite drastic happened to that arm, possibly wrenched above his head for the operation. It had been years since it had been able to range properly. I now know because of a few falls I have had myself, that torn muscles form quite solid swelling under the skin which is not detected by X-rays. It makes me feel sick to imagine how Don may have been treated in theatre.

This, I guess, is not that important, just indicative of the lack of concern and care. Another example is the infrequency of the notes taken by Spinal ward nurses. One set was made at 4.40pm, the next not until 4am the next day. This is ridiculous for

any hospital ward, much less a Spinal Unit. From here on until Don's respiratory arrest, the nursing notes differ greatly from my own recollections. If you just went by what they have written in the time before the arrest, no alarm bells would ring. It appeared to me that the more seriously ill he became, the less care and attention he received.

Much later, going through the notes, I discovered that there was an even more sinister reason for the pain in his arm, which they had 'poo-hoed' to our faces. After a Spinal nurse, to her credit, discovered the suction error missed by all the cardiothoracic doctors and other Spinal staff, the suction level was corrected and Don no longer complained about the pain. This is recorded in the notes. That suctioning had to be causing major pain, because Don had a very high pain threshold, and would not have complained much about a sore arm. We were never told any of this at the time, but all the doctors and nurses treating him knew.

Melissa, who lived in Coogee, Sydney, came in to see her father on Friday 13 April. We all had a good time and I took a photo of her and her dad with my mobile phone, not knowing this would be the last photo of him before those awful ones in the Intensive Care Unit (ICU). That morning, Don appeared a little easier in his breathing, but later in the day began saying a few more odd things and visibly having more trouble breathing. Later it became a sort of panting breathing and I noticed that his tongue was poking in and out as he breathed. He seemed unaware of this.

More than once I drew nurses' attention to it but was just told, over and over: "His SATs [oxygen saturation figures] are OK". This parroting "SATs OK", "SATs OK", went on that day and into the next, but no one seemed to be actually looking at my husband. Blind Freddy could have seen the increasing struggle he was having trying to raise his shoulders (diaphragm-breathing) to allow more breath in, which is the way quadriplegics breathe. Able-bodied people get ease from fluid and breathing difficulties if we sit up, but for quadriplegics it's the opposite. Because the diaphragm has, in effect, to lift the lungs, it's really hard work to breathe sitting up if there are problems. I noticed this different form of breathing when Don was first in this hospital in 1982. It kicked in as soon as the accident happened. Without this miraculous alternative way of breathing, few quadriplegics would survive until the ambulance came. Specialist Spinal Unit nurses should have known this as part of their training.

But they just looked at the machines and ignored the patient. Nowhere in their notes on the 13th and 14th did they record my increasing concerns and queries – even panic at later stages. Don had started to become, for them, a 'nuisance' patient. We had learnt from experience that the needier a patient is, the more some nurses will 'blank' them when they come into the ward. As loud as Don would call, there was more than one nurse who pretended he or she didn't hear. They even ignored me when I called. I would have to follow them out to get them to come and see him. I come from a family with a nursing tradition, and I know what is acceptable. My apologies to the good nurses – and there are many – but just as many in Spinal and ICU were, as Don said once on a previous visit to the Sydney Spinal Unit, "like a pack of bush pigs and with as much compassion". This comment came about one time after the "Lift Round", when wardsmen and nurses

(usually about four people) came to turn Don in bed, as a preventative measure against pressure sores. Like all quadriplegics, Don was unable to move himself to ease pressure. He said they were all gabbling to each other over the top of him, not noticing him much, and then he'd was dumped down with his paralysed legs all akimbo and with the urine collection bag all jammed up in the hinge of the bed base. I was able to rearrange his legs and pillows and un-jam the bag that time, and others, but if I wasn't there he would have to call a nurse to reposition his legs and check that everything was OK. Some turns were excellent, but many were not.

In a Spinal Unit ward after the surgery, Don was needy because of what they had done to him, yet we were made to feel like it was our fault. The patient opposite, a man called Norman, knew how to play the game. He kept his needs to a minimum. Disabled people and their relatives know that what I am saying is truth. Spinal nursing is specialised and demanding, as everything has to be done for a quad once in bed. Teeth almost never get cleaned in this Spinal Unit unless a relative does it. I have seen Fluid Balance charts bodgied up because no staff has bothered to give patients any of the cups of tea that are left in a line for them. That was in the days when nurses used to leave the charts at the end of the bed. They no longer do this, maybe because too many of us relatives were too inquisitive as to the quality of the care our loved ones were getting. I have watched quadriplegics bolt down their food like dogs before the nurse feeding them has to go, because otherwise they go hungry.

I remember in this Spinal Unit in 1982, one lovely young man called Errol who was a Quadriplegic telling us he had to do this. He didn't have many visitors to help him. Some patients don't get their lunch at all, or dinner. And heaven help them if they are asleep when the Lift Rounds come in the daytime. I have heard the team say, so we all hear: "Better not wake him – let him sleep", which sounds considerate but means the poor bugger may well get pressure sores. Good nurses will never allow this to happen to a patient, and there are many good nurses. I don't think there is any greater cruelty or sin than this sort of behaviour against helpless people and I have to hope that there is an afterlife where there is justice, because the people who inflict these cruelties are seldom punished by the system.

The uncaring attitude of many of the staff was part and parcel of the general rundown and demoralised condition of this hospital in 2007. The Spinal Unit was not even a pale shadow of what it was when Don was there in 1982. Then it was busy and alive and up to date. The Unit there now is ramshackle, with wards used to store equipment. Don and Norman's room was half-full of old furniture and other things, stacked about four feet high. I hung my coat and bags on the upturned chairs. The rubbish had the window position, not that you could see out of the windows anyway. They hadn't been cleaned for so long; the light coming in was diffused by dirt and grime. The whole hospital was like that. In the canteen they even started a short-lived collection to have the windows cleaned, before management intervened and put a stop to it. Later, front page newspaper stories described the hospital's dilapidated state as 'Third World' and 'disgraceful'.

The cardiothoracic doctors knew, or should have known, to go carefully with such a debilitated man, to at least do all the standard procedures before operating, to be conservative in their treatment and to know exactly what level the lung suction was set on. As Dr H.'s report recorded these things did not happen.

The fact that I warned them in the Spinal Unit for two days that Don was in trouble breathing and that it was getting worse progressively and no one acted – what name can I call that?

If I had acted towards him as they did and so caused his death, I would probably be, as his wife and full time carer, serving a jail sentence right now. I do not comprehend the difference. My carelessness would be that of a layperson. But how much worse were their actions, as medical experts? They acted with full knowledge of the lack of standard checks prior to surgery and without a comprehensive care plan. Neither Don nor I were told about the mistake after surgery which meant his lungs were suctioned at ten times the correct level. At the time, it was covered up. I could see what was happening to him but as a layperson had no idea that his bizarre breathing pointed to a possible respiratory arrest. I just knew my husband was suffering, but the doctors and nurses not only ignored my observations over a period of two days; they made the situation worse.

On Saturday 14 April at 5.30am, the Spinal Unit night intern reported in the notes that Don's oxygen levels were down and fluctuating. After a Pleurodesis, alarm bells should have been ringing loudly. The night doctor reported that the "patient was muttering to himself," yet only the day before, Don had been lucid. The doctor says his impression is that the agitation is due to hypoxia, or oxygen deprivation, and to maintain a Hudson mask. Nearly two days after lung surgery, Don is going backwards with his lung function – yet the more senior doctors all just ignored this. Their casualness was shocking. Don and I were not once told that the doctors or nurses felt anything out of the ordinary was going on. It wasn't until I obtained the notes after Don was allowed to die that I knew any of this. At the time I knew only what I saw, and that something was very wrong.

Then, a cardiothoracic doctor organised for a nasal prong oxygen delivery system – despite the fact that Don was visibly mouth breathing. He then recommended Don sit up, despite the fact that as a quadriplegic, sitting up always made breathing harder and worse. The medical staff did not seem to comprehend the simplest facts about the breathing mechanics of quadriplegics, as is demonstrated by this recommendation.

Oxygen saturation levels should be maintained at 95.1% and above, but Don's dropped to 89%. The nurse noted "patient muttering to self and disorientated." Now one would think they might be starting to get worried. But no. The cardiothoracic doctor writes he is 'unconcerned because patient post-operative'. With all the signs of a Pleurodesis failure flashing at them all, no one can explain to me how this happened. My husband came out of an operation smiling, clear-headed and aware, and here we are two days later, after a procedure known to cause acute respiratory distress, of which Don had all the markers, and the doctor supervising his care is 'unconcerned'. Poor Don. I didn't know what was happening or why. No one seemed to have a duty of care for him. He was beginning to be treated as if he was a damn nuisance or an idiot.

Again, the supervising doctor records in the notes that he wants Don out of bed and sitting upright in his wheelchair, and to go to six-hourly nursing obs. I thought they had already done that, unless I don't have all the notes. It took me a while to get what I did get, so who knows? The nursing notes after this, in

Spinal Ward 7D, are a disgrace. On that dreadful day before Don's respiratory arrest, they recorded observations at 12.25pm and then not again until 10pm. And this during a time I was running back and forwards to them, frantic with worry and panic.

Nothing was written in the medical records of what was going on. I had trouble even finding any nurses on that horrible Saturday. I went from ward to ward, over and over, because Don was so distressed. In my mind's eye, I can still see me running up and down the corridors, trying to find someone who would listen. Then back to Don who had begun gasping and panting and would fall in and out of confusion. I am still imprisoned by his suffering that day. I know it's like this for Melissa and Alison, but in different ways. My great comfort now is that I know Don is free of all suffering.

Today, I lost the plot again, just for a moment. I had to get it together because the washing machine repairman was due. It had been a good day. My friend Carmel and I had had photos taken, just for fun, make-up and all. Life felt normal and for a moment, I forgot. Sometimes I feel guilty for forgetting, but I know that this is a common feeling so I don't beat myself up over it. After Carmel and her husband Glen left, it came over cold and thundery so I went up to my cupboard to find something warm to put on. Don had a couple of blanket-type ponchos I like to wear. They make me feel closer, the colours and memories of him using these as blankets, and warm is good when you feel as raw and cut up as I do.

I pulled out the ponchos from underneath his shirts, and his shoes fell out in front of me. His shoes. Those shoes. Don had them for years. Quadriplegics don't wear their shoes out. It's the only cheap part of that particular disability. I shoved my face into them, hoping for some smell, some bit of him left. Nothing. Threads of fluff stuck in the Velcro, and they looked older. Time passing, I guess. How many times did I take those shoes off him at night? He had them for at least two decades. I remember sitting on the floor before him and getting them on all straight, under instruction. Always under instruction. Those who knew him will smile at this.

Don was always in charge, always aware. There was nothing that made him madder than when a home nurse tried to send him out dressed for the day with his pants and shirt on crooked. 'Near enough is good enough' was an attitude he loathed. We were paying these nurses good money, but I knew some of them resented his asking to look halfway decent for the day. I only mention this because it always struck Don and me as a strange attitude, to resent being asked to do the job you are paid for. Seems this is becoming more common. Good nurses just go about doing what they do, being compassionate and caring, but don't get noticed as much.

Is there anyone out there who wants to look like an idiot with their clothes all askew? People who have not loved and had close touch with someone with severe disability may not understand this. I remember that some of the nurses over the years would occasionally try to get out of dressing Don and getting him up in the wheelchair for the day, so they'd try really hard to find some small pimple or imperfection on his bottom and use that as a way to make him spend the day in bed. We would impress on them that any mark on Don's bottom had to be pointed out

and only if I judged it an issue would he would spend the day in bed. I came in on one of them, after being asked to come and look, and found her digging her nail into Don's bottom. He had a feeling something was wrong and asked me what was going on. When I declared he was able to get up, the look that nurse gave would have turned me to stone had my fire not been up that day. I remember Don being very angry one day because a nurse, who had used a washer on his bottom area and then tried to wash his face with it, got annoyed when he caught her out.

People react strangely when they get caught doing something that basic training tells you is unclean. I don't think some of them realised how close Don and I were. He told me everything, every day after they left; the good things, some of which were beautiful, and the bad things, which hurt him because he came to like many of the nurses over the years.

We had as many good nurses as we had bad ones, and so again the balance was struck, as Carmel reminded me one day. Don and I were one unit trying to preserve some sort of life for ourselves. An unnecessary day in bed for Don freed that nurse from 20 minutes of paid work getting him up, but to us it meant a whole day where Don could not do what he needed and my day had to be spent turning, feeding and helping him – which was fine when he needed to be in bed, but we knew when we'd been shammed and I know the nurses who shammed us. With some there seemed to develop a sense of "entitlement", and the quality of care would diminish over time. For those who treated him well however, I offer my eternal gratitude.

So today, I put that poor single pair of shoes back in his cupboard. Oh dearie me, how many times can a heart break?

CHAPTER 9

Respiratory Arrest

And here we go; my lovely gentle man is well on the way to respiratory arrest and consequent death five horrible weeks later, leaving us all. This man had suffered unbelievable pain and indignity over the past 25 years but it was nothing compared to the horror that was about to be unleashed on him. And because we love him, on us too. I will never recover from what I know and what I saw in the weeks that followed. What Don had to go through before death makes me feel physically ill and sometimes I find myself gagging as the pictures play again and again in my mind. I have to say I am glad I don't know what was done to him when I wasn't there, because I think I would have lost my mind if there had been anything worse.

This book is my way of freeing myself and our family and thus freeing Don. I am hoping to get justice for my husband. We daily relive a horror which was preventable and which arose from ignorance, arrogance and a fundamental lack of care.

On Saturday 14 April I arrived at Don's ward at 10.30am. He appeared a little disorientated. I was not told by nurses or doctors of his previous overnight agitation or oxygen saturation drop. He was saying a few things a little out of character and becoming increasingly agitated. Unknown to me, this was a side effect of carbon dioxide building up in his system prior to respiratory arrest. I was to see this a few more times when he was in ICU but did not know then what I was looking at. How could I? I had no experience of anyone having a respiratory arrest.

After Don's arrest the next morning, the admitting specialist told me he had visited Don at 10am on Saturday, half an hour before I arrived, and that he was "fine". I have found no record of that visit in the notes, but Don was most certainly not fine and a child could have figured that out. I wonder why the admitting specialist didn't have any concerns when he saw the fluctuating oxygen saturation levels. Why did he and other specialists appear complacent? Nobody has been asked this, to my knowledge. It makes no sense unless they just flashed Don a cursory look and called that a visit.

In the next five weeks we had to question more and more.

I began mentioning my growing concerns to the nurses – to Don's nurse, to any nurse I could find, as his seemed not to be there all that much. I also mentioned the by-now visible sign of his shoulders and chest moving up and down, trying to breathe, more and more laboured as the day went on. Not one of my many comments is noted on this terrible day. I find this omission appalling. They did not even bother to make one note.

Alison rang me on my mobile that morning after speaking to Don by phone at 11am. She was very concerned because he was not really making sense and had also forgotten Melissa's visit the day before. This was very unusual because when he saw Melissa, he was over the moon and as mentioned we took a mobile phone snapshot to mark the occasion. He had started talking to Alison about the

Consumer Price Index and other business matters she had never heard of. She was very worried; wanting to know what was going on.

Don became really agitated and his comments hard to follow. The notes begin to mention 'post-op problems' but not that Don was gasping and panting, struggling to breathe, nor that he had gone so quickly from well and alert to hallucinating and in obvious distress. And had it indeed been a post-operative reaction, why were they doing nothing about it? Their glib complacency puzzles me when everything happening to Don pointed to a failed Pleurodesis and an inflammatory response. Something was terribly wrong in the way staff were reacting to his visibly worsening condition.

At 1.30pm, as ordered by the doctor, Don was lifted out of bed and positioned in his wheelchair. Straight away his breathing became even more laboured and at times he appeared to be in a sort of waking dream, making strange connections. For example, Norman in the bed opposite was reading a book with the author's name on the back. Don fixated on that name and said that was the name of his doctor. But then he flipped back to being totally lucid and frightened. He knew something was terribly wrong but did not know what. He was terrified.

I begged a nurse to return him to bed, but she refused. He suffered three hours of extreme torture trying to breathe against gravity. He had a respiratory arrest that night. Why were they all so ignorant of his condition? The specialists should have known not to place someone whose lungs were being suctioned in a sitting position, as this can lead directly to acute respiratory distress. This is stated in the literature, and this is what happened. What on earth was going on with these people? Until any or all of the doctors or nurses who were there sit across a table for some hours with Melissa, Alison and me and tell us what they thought they were doing, I have nothing in front of me that makes any sense at all. How could they make not one mistake, not two, but multiple mistakes, all compounding each other? Mistakes at every turn.

A short while after they sat Don up, he got me to get his toothbrush so he could clean his teeth. Then a little while later he asked me to do it again. Then again, about half a dozen times at least. He must have had a really bad taste in his mouth. He would forget that he'd asked me to do it for him. A little while into sitting up, he got me to ask the nurse if he could he go back to bed, because he was feeling nauseous and having increasing trouble breathing. He was swinging from lucidity to hallucinations and then back again.

The nurse told him quite firmly to wait until the next lift round at 3.30pm, seemingly blinkered and oblivious to his obvious suffering. I offered to help her get him back into bed, but she seemed uninterested and was uncooperative. It seemed that no amount of visible suffering could make the nurse deviate from whatever plan she was running to. In the hospital, I couldn't get him into bed as I could at home, where I had our hoist. I could not even lift Don in his chair to ease pressure at home because my lower back was a mess and there just wasn't any lifting strength there. I'd tried to move a full 44-gallon drum when I was 29, so my back problem wasn't caused by caring for Don, just my own youth and stupidity. Finally, the lift round came at 4.30pm, and Don's breathing eased as he sank back in bed exhausted, but his condition was worse than when he went into the chair.

Because he was becoming increasingly dangerously ill, the build up of carbon dioxide in his system was making him very agitated and he was breathing fast. He did not seem to be having his breathing rate monitored. On six-hourly obs., he was not being monitored well at all. Nursing staff seemed entirely unaware that the man they were dealing with was totally unlike the one who arrived on the ward less than two days previously, or if they were, entirely unconcerned by it. I don't understand this. I am not a nurse, but anyone could see something was wrong. Don just wasn't making sense most of the time, and then he would. That would make them happy and off they'd go, parroting "SATs OK!" At my insistence, a nurse came around about 6.30pm and asked Don very loudly who the Prime Minister was and when was Don born and other questions, all of which he answered correctly, and off she went, satisfied. Seconds later he was seeing things in the corner of the room and talking away about nothing. He seemed to settle after a while, although he was still doing that strange breathing, like watching a frog or lizard's tongue dart in and out. I had never seen anything like this. I had no idea what it meant and never considered how dangerous it was. It was beyond my experience. I was, as was Don, just frightened because it was strange and it was distressing him.

I left for the subsidised accommodation for relatives of country patients in which I was staying about 7.30pm totally exhausted, emotionally and physically. I only wish I had stayed, but I had no idea this would develop into an emergency; I just knew something was wrong. I wanted to be back there early the next day to catch the doctor and try to get some decent care for my husband. I spoke to Norman as he had better hand dexterity and asked that if Don couldn't ring for a nurse, would he do it. Sometimes Don would lose the buzzer and could not get the nurses' attention and they did not stick their heads in very often. Don and I knew he had become a 'nuisance' patient. I had no one I could ask to come and sit with him all night, which is what should have happened. I know in hindsight I was on the edge and just coping. Most of the time I was feeling light-headed and spaced out. The previous months had been dreadful for us both and I had nothing left and needed to sleep.

I have relived that day over and over, wishing and wondering what I could have done differently. I know Don knew I did the best I was able to do, and so I have accepted that I am only human; that I did my best. That helps me live with myself.

I remember walking five minutes down the hill to the motel in a daze, shocked to my core at what had happened. I can't recall how many times I went to those nurses, sick with worry. "SATs OK" was all I ever got. Despite my dozens of pleas for help, not even one nurse recorded any of them, as they were required to do. Don knew how they were treating him and knew he was in trouble, as did I. We just had no idea how bad it would get.



That night, at 3.51am, Don had the first Respiratory Arrest and was transferred to the Intensive Care Unit. The exact sequence of events was not to become clear until much later. In fact, because of the inadequacy of the notes made by staff,

it still isn't completely clear to me over two years later exactly what happened in the hours between my leaving Don and being woken in the early hours by a phone call from the ICU. It probably never will be.

Before I left that evening, I told Don's nurse that if at any time during the evening and night he called or needed me to ring me, and that I was just five minutes' walk away. Earlier in the day I had gone to one of the nurses at the desk and said that if anything went wrong I was to be called. She went to my husband's file and said it didn't show my mobile number or where I was staying and that there were no details on Next of Kin recorded. This despite the fact that I later found all that information in the notes sent from our local base hospital. I had given this information when I went to the admissions office at the Sydney hospital, and had also posted it on the wall near his bed.

If I hadn't thought to actually ask to be notified, they would have had no numbers for me because of their sloppiness.

I fell into bed that night and just crashed, still partly dressed. The call from ICU came shortly after 4am. Despite the fact that Don had been calling for me for hours before, as I later discovered, that was the only call I had from the hospital. On the morning after Don's arrest, when I went to collect his things from the ward, Norman told me Don had kept calling my name, for two or three hours before his arrest. Norman was clearly distressed by what had happened. Yet the nurses failed to phone me, as I had specifically asked them to do. It broke my heart that Don wanted me so desperately but I didn't come. He must have felt so abandoned and frightened. As he was not thinking normally, did he think they had called me, but I had deserted him? For 25 years I was always there when he needed me, but not at this worst crisis. Later when I was alone I cried for hours, but never in public.

The nurses should have phoned me the first time he called for me and also as his condition deteriorated. He called and called. He trusted I would come, that I would always be there as I said I would. Even rewriting this makes my stomach turn. I knew how hard it had been for him to get words out and hold a thought the day before; how much worse must it have been in the shocking lead up to the arrest? According to Norman, much of this time Don was left unattended and calling my name. These events are heartbreaking. Just for this there should be an inquiry. But the Health Care Complaints Commission has declared all of this 'acceptable'.

When I went to collect Don's things I found them strewn all over his side of the ward and bed. It took me well over an hour to pack up all his property: his clothes, special pressure cushion, various disability aids, sheepskins, personal papers, essential \$2,000 air mattress and even vital medication that should have been with him. I had to go looking for his \$8,000 wheelchair and found it in another ward. I mention their monetary value because of how precious these things were for Don, but as they'd been left lying around, they could have been taken by anyone. I packed up his locker and cupboard and got everything into some form of order so I could manage to take it to him in the ICU.

All this time I was in a state of sick shock about what had happened to him and I needed and wanted to be with him. No one from the Spinal ward came near me

or tried to help that I can remember, and I have tried to remember. I could not have been more invisible. They turned away, the one or two I recognised. No one asked if I needed help, nor had anything to say to me at all. No help was offered to get Don's quite considerable amount of stuff downstairs to ICU. There was too much for me to handle and take at once, and I did not want to leave it, as things go walking and were needed. Not one nurse asked me if Don was alive or dead.

Finally I rang ICU and they sent a wardsman. I felt angry and humiliated at having to scabble about like this at such a terrible time, and that young wardsman was stunned when he realised nobody had offered to help me. The Spinal ward nurses had one less patient, after all. The kindness of people like some of the wardsmen and women, just little throwaway kindnesses, means more to people than they would ever know. While some of them might be indifferent to what happens to patients and relatives, others were very sensitive. Funny, but I can remember exactly what this one young man looked like, and I also remember Norman. The thoughtfulness of wardsmen and women and a few doctors and nurses was hugely appreciated, and always did much to lift my spirits. I truly hope they know how much it helped. When kindness was given I sometimes fought tears of simple gratitude. It was these tears of gratitude that I found hardest to hide.



How did my husband have a Respiratory Arrest? How could both of Don's lungs collapse, as I was told in a later hospital report, despite all of my warnings and pleas? The Spinal Unit specialised in spinal medicine; how was this arrest allowed to happen? Staff told us there were no clinical warnings. The truth is, there was nothing *but* warnings.

Everything that was happening pointed towards an impending respiratory arrest. Don's body craved oxygen. Anyone could clearly see he was only breathing through his mouth, but in spite of this, the specialist ordered that Don receive oxygen through his nose. So it was there, but he couldn't get any. They didn't appear to notice his tongue going in and out. His breathing was faster than it should have been and he was clearly distressed. All signs of imminent arrest, as I learnt in ICU. I was to see this same build up four or five more times.

More than once I was told, "Don't worry so much", yet every one of my concerns proved to be fully justified. Why was this? How could this be true of me, in contrast to medical specialists? The answer is that I was with Don for 35 years. As his wife and carer, I was with him seven days a week, almost 24 hours a day. I could communicate with him and I understood him and his needs. I was open to anything or anyone who might help. But above all of this, I loved him with all my heart.

The attitude the nurses developed towards Don was reprehensible. It wasn't about how busy they were, as they were quite pleasant and patient with Norman. But because of the effects of the slow build-up of carbon dioxide in Don, and his agitation and my constantly trying to warn them, we were obviously annoying them and were therefore 'blanked'. Many people with chronic illness know about

this blanking. Apart from their routine 'duties', it was only when I made them come in to Don that they took any notice at all of him.

What was happening to Don was a text book reaction to a failed Pleurodesis. Common sense should have dictated that my concerns were taken seriously. During the days I was watching him every minute, not briefly every six hours or so. My observations, though relevant and accurate, were ignored – again and again. Instead, Don's medical treatment and the infrequent observations were almost always perfunctory. I wish it was not so, but sadly, we were right at every turn. Even Alison, speaking on the telephone from Melbourne, could tell something was very wrong.

Don's fear and increasing trouble breathing were visible and audible. How could they not see this? Why did they not act? Are they that badly trained? When I look at their sparse and sloppy notes, although they kept telling me "SATS OK", even that was a lie. His "SATS" were not OK. They were up and down all the time. Why did they not consider that his increasing delirium might be caused by increasing carbon dioxide, as evidenced by his strange breathing? All of this is well known medically. Why weren't the senior doctors aware of what was happening? Once acute respiratory distress syndrome, or ARDS, occurs after Pleurodesis, death is likely, much more so for a weak and debilitated quadriplegic. The specialists had to know this. Even healthy people have a huge battle to survive. And there is no doubt that the unnecessary, highly dangerous and failed Pleurodesis caused the ARDS which finally caused Don's death.

What are you supposed to think when someone you love is treated like this? What should you feel? What should you do? I don't want to hate but it's so hard when the images of what happened to Don flick randomly through my mind and haunt my night time waking and sleeping hours.

When I was sitting next to Don in ICU after his arrest, the ICU doctor mentioned that if Don made good progress, he would be able to go back to the Spinal ward. As doped up as they had him, and with tubes everywhere, Don thrashed his head from side to side. He was terrified. Literally terrified. His reaction looked like that of a trapped wild animal – it was that extreme. I don't know what had happened to Don in Ward 7D after I left on the night of his first Respiratory Arrest but his reaction was, and still is, of grave concern to me. Something dreadfully wrong happened to him after I left, in the build-up to the arrest, but I sense I will never know unless someone breaks ranks and tells me. They probably don't even remember if the truth be told.

Don had for years suffered great pain and indignity and he was a brave man. This reaction was unlike anything I had ever experienced with him. I hope Norman, the patient in the bed opposite, can give some input on what happened, if he is still alive.

The Road to Intensive Care

“Acute Respiratory Distress Syndrome (ARDS) can occur up to 72 hours after Pleurodesis”. This comes directly from the official Product Information Sheet concerning such operations. Yet the admitting specialist surgeon said it could only happen in the first 24–48 hours. How could it be that he did not know this most basic and important fact?

From 15 April to 17 May 2007, Don was in ICU. No matter what happened there, no matter his suffering, not one minute of it needed to happen as he should never have been there. An Intensive Care specialist wrote in Don’s notes: ‘I suspect his quadriplegia has left him with marginal respiratory reserve that has rendered him incapable of ventilating after his Pleurodesis’. What I see he means here is because Don’s breathing was severely limited due to quadriplegia, that the operation compromised what little breathing ability he had so as to inevitably cause his death.

I studied closely the observations made in the Spinal ward and the length of time between them. On 14 April, the last recorded notes of the nurse – whose name I can’t read, as is the case with most of them – were done at 10pm. Then there is not one handwritten note until 7.50am the next morning, and that appears to have been written in retrospect in a block so as to fill in all the time between. If there are any decent observations taken then, please someone, point them out to me. I can’t find them.

On 15 April, the Spinal night intern begins a set of notes. There are three pages of these notes made by that junior doctor, and others. No times are noted at all, but this was obviously all written after the arrest. There is no mention of Don calling out for me. Most of the notes are indecipherable scrawl, so how on earth anyone coming along days later could understand what happened is hard to work out. Writing this account, it has taken me a great effort to understand even the most plainly worded notes, because too much of it is scratch and scribble. Too many notes cannot be read, nor translated from both their shorthand and also their illegibility. It is very dangerous.

A day or so after Don’s arrest, I contacted the hospital’s ‘Patient Advocate’. He advised me to raise my concerns with the Spinal Unit’s Nursing Unit Manager, or NUM. I spoke to her about how frightened Don was of coming back to the Unit, and my concerns as to whether, if he were sent back, he would be properly looked after. Instead of understanding my fear she said, quite tartly: “He didn’t have to come to Spinal in the first place. We were doing him a favour by taking him as he was admitted as a thoracic patient.” After what had happened to Don in the Spinal Unit one might assume a little compassion. You would think a Spinal Unit nurse would have special understanding of what a Respiratory Arrest and Acute Respiratory Distress Syndrome meant to a man who was a quadriplegic. It was a death sentence. But no somehow we were to blame again and they were doing us a favour. She showed no compassion, no acceptance of any problems in the Spinal Unit.

I wish I hadn't wasted my time and caused myself even more stress. It was a useless exercise. Don was this NUM's patient however he had been admitted under. He was Spinal because he was quadriplegic, and the one area in the whole hospital which should have understood his needs was this place. Instead, they treated him like a nuisance. The hospital's "Patient's Advocate" should have come with me to follow all this up and actually be my advocate – all he ever did was to tell me what to do. There was no support. If he had attended, her responses would have been less confrontational. The Patient's Advocate later made statements to the hospital's internal inquiry into what happened to Don which, if accurately reported by the inquiry, makes me wonder whose advocate he really was.

But the Health Care Complaints Commission calls it all 'acceptable'.

Back to the Spinal Unit's night intern. Again there is no time given when he notes that Don's SATs were down to 89% 'with probe in correct position.' He notes that Don 'complains of being more short of breath than previously.' Then he adds 'Nil signs of respiratory distress' and 'SATs back to 95%'. Shouldn't a doctor have thought: "Why on earth are the oxygen saturation levels fluctuating like this? This is not normal." But no, once he got the levels back to normal off he went, no inquiry, no curiosity, and I say a breach of care, yet again. He should have acted. Don may still have died, because I think his lungs were already too badly damaged for a quadriplegic to survive but my God, the suffering and terror they could have saved him doesn't bear consideration.

What time did the night intern write that note? Was it an hour before Don's emergency, two at most? Even to rewrite this causes me such pain. They should have called me. They should have protected him, got him to ICU and treated what any fool could see was happening. He was just basically abandoned to it. I want to know why those people did not call me. I have the right to ask them at what time exactly did they finally realize how desperately ill Don was. I get the feeling he almost had the arrest before they actually did anything constructive. By then it was too late.

The Hospital in their reports sent to me and signed by Dr H. admits that the Night Intern should have had a senior person to liaise with.

In the early hours of 15 April – that's as close as I can guess, the notes are so poorly written – someone called S.Y. visits (no time given) and notes 'SATs down and agitation and ATSP' (meaning 'asked to see patient'). Half the notes are illegible. Something Peter Garling in his later Inquiry into Acute care services in NSW Public Hospitals stressed was a huge problem. He had recommended all NSW Public Hospitals move over to full electronic recording of notes. Hopefully this will be the case by the time this is published.

Whatever happened to my husband that night? At some point just after the respiratory arrest, it is mentioned that the admitting specialist has declared: "Talc Pleurodesis reaction unlikely". A rather quick diagnosis without any testing, wouldn't you say? But as the surgeon who performed the Pleurodesis, he would be inclined to say this, considering what all the ICU doctors added in the dreadful weeks that followed. Even one of the admitting specialist's own team wrote 'failed Pleurodesis' later on. Why would the admitting specialist make this statement, before he had time for a proper examination?

As recorded on page 2 of Dr H's letter it is a fact that Don was given a Pleurodesis, with no expected and accepted pre- and post-operative procedures. From our research it is reasonable to believe that he was unlikely to survive this operation. It all beggars belief and has no explanation.

The HCCC said this was all "acceptable"

I can't decipher the first notes made in ICU. These notes were written by the admitting specialist and a member of his team, also a specialist. I cannot read them. They need translation. But another doctor notes at 7am: 'Respiratory Failure and Inflammatory Markers. ? Talc reaction.' Then there is the record of the medical emergency event, which is legible. Don's respiratory arrest occurred at exactly 3.51am. Later, I watched Don come exceedingly close to, and also experience, further respiratory arrests in ICU. It was shocking and painful suffering for him. What in God's name was he like in Spinal to get to that stage, and how was it allowed to happen? Someone has to be accountable for this, as well as the surgeon who did the Pleurodesis and left Don so badly monitored. It appeared that in Spinal it was a systemic issue of attitude and a blasé lack of care and attention by nurses and doctors. I now find in the nursing notes, all written in one chunk at 7.50am on 15 April that at one point Don's oxygen level had dropped to 83%. Again, the nurse has not noted the time. It seems obvious to me that this sort of incomplete, sloppy notation is fraught with danger. Time is all-important.

Among the ICU papers are the notes written up by a Spinal Unit nurse for Don's last hours on Ward 7D, when it was finally being acknowledged that something was going terribly wrong. As mentioned, these notes were written retrospectively and are sparse on times. Put them alongside the observation sheet, which is not even dated, and it is clear Don was left unattended until it was too late. Please explain, Commissioner Pehm from the HCCC – how can this be 'acceptable'?

Yet the HCCC is our only 'investigative' body in NSW. Hence this book.

The litany of mistakes is made worse by illegible handwritten notes. Even though there is some medical shorthand, most of it is just scribble. Scribble. Scribble in what used to be one of the top hospitals in the Southern hemisphere.

Months after I requested and received the hospital notes, I realised there were no observation charts from the three and a half days Don spent in Spinal 7D. I noticed that even though I had asked for all the notes, they hadn't sent the X-rays and scans nor the flow charts from Spinal and ICU. I rang them about three times and finally they responded and posted me the one sheet of A4 paper of observations I mentioned earlier. Don was a high level quadriplegic with serious and complex medical problems, who had just had dangerous surgery on his lungs. They had botched the suction level. Plain and simple and they have admitted this. The lack of observations and their sparse recording is disgraceful. In no way do the notes reflect what was happening – but they clearly show Don was not being cared for adequately and safely. At home I would never leave him for that long, even when he was not ill, without making checks – and that was for 24 hours a day seven days a week for 25 years. I would have been negligent if I had left him like they did, and I am just a housewife.

Clearly, you cannot educate anyone for compassion and common sense. If you haven't got it you haven't got it. But the training of these doctors and nurses has to make them accountable. They do have to have a duty of care and they should always act on the fundamental precept of the medical profession: "First do no harm".

CHAPTER 11

ICU Early Days

When the phone call which should have been made hours earlier came at about 4am, I rushed up to ICU. As I made the short walk, I called Melissa and Alison and then my sister Veronica. I wasn't allowed into see Don straight away, so I phoned his brother's house and spoke to his wife. They live in Brisbane, as did my sister and Don's nephew Rod, who arrived later that day.

Don was in ICU from 15 April until the afternoon of 17 May 2007, when he was 'discharged' on a ventilator. We were told the ventilator would be taken away as soon as he arrived home and that he would die a few hours later. This provision was the only way they would work towards getting him home. As Don knew he was dying and had a horror of dying in this hospital, he took the offer.

I have spoken with our daughters and my sisters about this five-week period, and especially that dreadful last day, and we agree that it was as if we were all just going through the motions in a state of shock, such that it all felt unreal and surreal. Some things which happened in those last days are only just starting to sink in for us. I had whole periods when the surface of my face felt either numb or prickly, and at night when I looked at myself in the mirror, I felt like I was looking at a stranger, a robot who had my face. It was bizarre. The atmosphere in our part of ICU was that of total chaos. There seemed to be a shifting sea of faces, with nobody wearing any name badges. It seemed almost like a sensory assault at the time. My sister Veronica likened it to the painting by Matthias Gruwald 'The Temptation of St Anthony'.

No matter what happened to Don in Spinal, and it was an awful few days, the five weeks he spent in ICU was the stuff of nightmares. He suffered dreadfully. I watched my husband's sister Judy die painfully from cancer over a three-month period, which even the palliative care nurses involved described as a 'disaster of palliative care'. That experience was graphic and shocking. But this was different. It was so impersonal; dehumanised. Everything followed a set process, and it seemed the process was much more important than the person suffering. There was little compassion shown to my brave husband. At least the people surrounding Judy were filled with love for her. The nurses were kind and the doctor caring, as they should be.

Don would not have ended up in ICU at all if he had had a member of the Spinal Outreach team (which once visited us at home) as his admitting specialist. This specialist told me she expected he was being sent to the hospital for, "*a simple lung drain and biopsies*". She spoke at some length about this to me soon after Don died.

There is not one bit of doubt what caused Don's respiratory arrest. Most of the ICU doctors and respiratory doctors mention failed Pleurodesis in their notes. When I asked and asked them over those five weeks, not one of them would tell me the truth. Yet their notes are damning as to the cause.

Don's suffering in these five weeks was so shocking to watch, so awful, that I have trouble remembering a lot of details. What I do remember is hard enough

to bear. It was as if it was just one long, continuous, never ending day; a day full of filth, cruelty and the unbearable pain of watching my lovely husband suffer more than I thought anyone could. Judy's son Rod summed it up in a recent email where he described his impressions of ICU and Don's treatment. It all just flooded back in a wash of what I can only call horror. Somehow, maybe for my own sanity, I had forgotten the worst things.

Rod wrote:

"I recall arriving at the Sydney approx 10pm Sunday night... after talking to Melissa that afternoon I could tell that things were not good, this why I flew down from Brisbane on the next available flight. I strolled through the hospital after visiting hours with a backpack with not one security check reaching the ICU ward, this alone sticks in my head, that was only the beginning; once I reached Don's bed I found my uncle's arms strapped to the bed and his mouth gagged holding in two plastic tubes, the tension on each corner of his mouth was painful just to look at. After greeting Don with "G'day mate", I had to hold back the tears thinking, "You poor bastard what are these people doing to you?" I actually said to Don, "You are a brave bastard", to try and give him some extra strength, even well knowing that a Mackay will fight to the very end to live. They have an inner strength. I stayed for an hour or so.

When I returned the next morning I remember I was actually appalled by the state of the hospital, it was filthy. The floors, the walls, the toilets, the elevators you actually felt you were in a third world country, I clearly remember thinking this. Then there were the nurses, one man (this is in ICU!) who could hardly speak English. Not one was helpful in explaining Don's condition. The doctors, well they seemed non-existent, apart from one tall doctor; however she would not even acknowledge you were in the same room. The next couple of days all I tried to do was be with Don and talk about old times. Not once did a nurse or doctor try to comfort Don or explain what was going on with him."

When I read this, it all flooded back. No one explained anything. They thought they did, as I read in the ICU notes that we 'understood' everything they said, but their so-called 'conferences' were a joke. We were not informed when Don contracted MRSA and he was moved to another part of the ward. I had to find where they had moved him to. I was not told when the MRSA and then the infection *Klebsiella Pneumoniae* went to his lungs until about four or five days later when a nurse happened to mention it because I noticed her suctioning up bloody mucus from his lungs. ICU felt like a madhouse with the inmates running the show. I sometimes felt that the patients and relatives were the only sane people there. There were many times and incidences too numerous to mention when I was kept uninformed and Don, who could hear and understand, was just entirely bypassed. He had no rights at all. The reasons for the extreme agitation he displayed in there were never explained to us. There was a certain amount of juggling about with his medication for extreme pain and his anti-anxiety medication, which would not have helped, but we were not told about that either.

All the time Don was in ICU, even though I asked many times, I was never told the cause of his original respiratory arrest in Ward 7D, and never told why he was unable to manage off the ventilator and had to be reintubated five – or was it six times? I lost track. A good quarter of ICU notes, from both doctors and nurses, are illegible, which is dangerous as a day or two after being written it would be impossible for other staff to really get the full gist of what had happened and what had been written. This just added to the lack of continuity. But now I have read their notes, or the ones which are readable at any rate, it is clearly evident that the doctors and nurses, and most importantly the respiratory doctors, knew exactly why Don had his first arrest and remained reliant on a ventilator until finally he was so diseased, so septic with their infections, full of fluid, his lungs full of hospital infections, that he was ‘discharged’ to die. Unbelievably, Don does not appear in the death rate of that diseased hospital; he was classified as a ‘discharge’, not a death.

Frequently the notes say his respiratory arrest followed a failed Pleurodesis, or words to that effect, and that he had developed ARDS following an inflammatory reaction to the talc. They all knew. Yet when I asked one of the respiratory doctors if the Pleurodesis may have caused my husband’s condition, he became aggressive and told me I was spending too much time worrying about this and should worry about other things. I said to him that he had no reason to speak to me like that and if it were his wife or child in here like this, how would he feel? Later he came back to say he was “sorry I felt that way”. Not exactly an apology. Melissa and Don watched this exchange. She was very angry and I have no doubt in the world that if Don could have raised himself out of that bed he would have laid that unctuous doctor flat for talking to me the way he did, with hands on hips and pelvis thrust forward in a very aggressive and intimidatory stance. Not one you would expect a doctor to use in front of a dying man and his family. But in the notes, this doctor wrote exactly what had happened to Don. At the time I asked him, he knew the truth. He refused to answer me. He should be called to account for that.

I thought it was a legal requirement that doctors fully inform patients about the cause of their condition and every relevant bit of treatment decided upon, every infection. In fact, we are meant to be kept fully informed at all times. But as it was, they only included us when they wanted a signature on a bit of paper or if we demanded to know so often that they would call one of their damn conferences as if they were doing us a favour. Just having loved ones in Intensive Care shattered relatives, without this sort of treatment. One day I asked a young man, whom I found in tears in the waiting room, what was wrong. His mother had been badly burnt and he seemed to be always on his own. He was terribly worried about her and, like me, in shock. He said that when anyone tried to get information out of them about a relative, “they act as if you are trying to steal their lunch.” This was spot on. It was as if you had committed an offence, or needed placating. There were few exceptions to this that I saw.

Furthermore, the duty doctors seemed to all disappear after about a week and a new set would come in. As the notes were so poor and illegible, mistakes in times and dates were made and perpetuated by sloppy record-keeping. In the notes, Don went from having a diving accident in 1982, which was fact, to a driving accident in 1988, to having a driving accident in 1982. Then they got it right, as a diving

accident in 1982, until the last doctor flipped it back to his being a quadriplegic for only 15 years. Even in sorrow, you have to laugh. In between the tears I would find myself starting to laugh like a crazy woman. They made so many and such stupid mistakes, and even tried to tell me (incorrectly) when the accident had happened – as though I wouldn't know! This is just one minor example. The HCCC later stated that much of the information we requested was passed on 'verbally', but we experienced little of that – and anyway, how does the HCCC know that, I wonder? Maybe because the doctors and nurses involved said so.

Don became what they did to him, and by the end not one of the staff had any idea of the original person who entered that place.

One nurse, the soul of tact, even said to me over his bed, when he was wide awake and could hear, "Is he always like this?" I don't remember my answer, but when you muck about with ventilators and drugs, bugger up fluid and take so much blood the haemoglobin levels were too low most of the time, why would an ICU nurse not have the common sense to comprehend what had been and what was being done to him? It's got me beat.

Not good enough for a 'modern' Intensive Care Unit in 2007. It's probably still the same in 2010. Nothing I have seen, understood or been told gives me any faith that a patient in the same condition as Don would not be treated in the same disgraceful manner today. As far as I know things as bad as those that happened to Don have happened since then, are still happening now and will continue to happen – because there is no one to stop it. There is no effective body to make the hospital and its staff accountable. No will to comprehend what it is they are doing to people and their lives inside that dark metropolis.

I have also noticed that when I go through the notes, I can't find Don's ward and bed changes noted. He had four position changes in ICU and yet there seems to be no mention of when these happened and to which bed he was taken. There's no real central nurses station which serves all of ICU, so when you turn up to see anyone in Intensive Care and they're not where you last left them, the first horrible thoughts are accompanied with a sinking feeling, "Has he died and they haven't told me?" – which is entirely possible in that place, based on past experience.

I am sure most staff in ICU had no idea that when Don was admitted to the Sydney Hospital he was 'alert and orientated'. Some of them expressed genuine surprise when they asked what he did and I told them that until earlier that year he had directed his own company and successfully run and maintained a large commercial building which we owned. Not that that should matter at all, but it showed me what their attitudes were. If he hadn't been so physically disabled I doubt this would have been so pronounced. There was one male nurse from somewhere whom none of us could understand. I had asked the other ICU nurses what on earth he was talking about and they thought it was funny because they couldn't understand him either. Yet he was looking after critically ill people who could die at any time. He annoyed me particularly because he wouldn't back away when I was with Don and went into these laborious and unintelligible explanations of Don's quadriplegia to me – as if I needed it explained! I'd be trying to talk to and be with Don and there he was in our faces,

doing nothing but listening to everything and constantly interjecting his vast knowledge in his strangled English. He was so ill-informed he frightened me.

One time, when a nurse was suctioning Don a part of the equipment fell onto the floor. Melissa and I saw that nurse pick it up and put it back in my husband's mouth, bold as brass. This was only days before the bacterial infections MRSA and Klebsiella Pneumoniae invaded his lungs so disastrously. Later, friends of ours saw another nurse do exactly the same thing, not too long before Don died.

Another time Melissa and I noticed that Don was very nauseous. We saw a lot of clear fluid coming out of his mouth and running down into his beard. We called his nurse over to suction him so he didn't choke. She was quite begrudging and on her way over complained that she'd just suctioned him. She did it again and then just walked off, leaving us to clean Don up as best we could. Then we saw it happen again and had to call her over once more. He was her only patient, but she was quite angry. We told her he was really sick and asked if she could give him an anti-nausea medication that worked well for him at home through his drip. By this time he was wet from this fluid from his mouth running down his neck, behind his head and underneath his shoulders. He was cold and shivering, feeling really ill. He had so many tubes, we asked her to help us clean him up because we were afraid of disconnecting something. She told us he'd have to wait for the lift round. That was that. We cleaned him up and got under him as best we could and he watched our faces with the saddest eyes. Poor Don. How could she do this to him? How could she act so horribly towards a suffering and dying man? Who knows what her name was? Melissa remembered that she was "*a harshly spoken English nurse*". Melissa's words. This nurse was horrible to Don and very slow to act in any direction. Some of them seem to even resent being at work at all.

Here again, my sincere apologies to those nurses who cared. They carried the others, and did their best to be compassionate inside a disgracefully run, run down public hospital. I remember a small fair-haired nurse who always sorted out the cables and tied them together and got the room in order first. I remember a dark-haired one who wrote lots of notes and really took notice of what was going on. There was a tall slim one who wore her long pants on the hip and was excellent and another who covertly told me about the "Top Secret" pressure area.

The staff had hidden from Don and me that a pressure sore had developed under his scrotum, but this one nurse had the decency to tell me, after her shift caring for Don ended. Why they thought it acceptable and correct not to tell us is hard to decipher. Any pressure sore developed in hospital is caused by bad nursing practices. That's it in a nutshell. No excuses. If I, basically alone in the house with Don for all those years, could ensure he never had a broken area of skin, or pressure sore, even when he spent six months straight in bed, how on earth could this happen in Intensive Care, with shifts of nurses and one nurse to each patient? And what purpose and whose purpose did it serve to hide it from me?

There were others too, over the long five weeks but I am sorry, I can't put any names to faces because none of the staff had name tags. How they work in that system cleaning up the messes and mistakes others leave for them is a miracle.

As I go through the notes for each day, almost all the nurses have written that Don was 'agitated' or 'extremely agitated'. The cause was never explained. As a C5/C6 quadriplegic, when Don was upright in his chair he had a little arm movement, no hand movement and little strength. Confined to bed, Don's arms were even weaker. But almost every day, Don's arms had to be tied to the bed, and he would be constantly pulling on the restraints. Sometimes the agitation was so extreme he would be able to lift his back off the bed by pulling on those restraints and this would go on for hours, often all day. He had never been able to do that in the whole time since he became a quad in 1982, and then he was a young healthy man. This went on for five weeks, and it was awful to watch.

Even I had to tie his arms down on the really bad days, every time I left his bedside because he tried many times to pull out the ventilation tube and he would get his hands all tangled up. I hated tying his arms down. I tried to do it as gently and loosely as possible so he didn't feel so restrained.

I knew his agitation had many causes. A lot of it was just uncontrollable movements, and he was on so many drugs often he was not truly with it, although he understood me and we had a lot of eye contact. But I know also that he wanted those tubes out. He knew the consequence of this was death – full stop. He had asked me some months before that if ever he was unconscious and on a ventilator, I was to make sure he was taken off. No quadriplegic was going to survive the massive damage done to Don's lungs and he knew it. I knew it. The staff knew it too. I am stumped as to why they would not admit it. He did not want to be like this. Being a quad, a slight flu is enough to kill. Don was never going to recover from the massive damage Pleurodesis did to his lungs. I know – not believe; *know* – he knew that and that he had made his decision and wanted out. Removing a ventilator from a morbidly ill person is not euthanasia. Euthanasia is actually introducing something which actively causes death. There is a huge difference.

Don had the right. But they kept doing what they were doing, holding out little slivers of hope, in a hopeless situation. Some of them knew what he was doing too. But I saw almost nobody medical give him any comfort for the misery of his dying. There were a few notable exceptions.

At this time NSW Health was not just broke, but deeply into the red. After his death I was told by Area health Service's representative that it would have cost over \$100,000 to keep him alive in ICU. None of this makes sense to me. He was dying. He was ventilator-dependent and had no hope of ever being able to breathe independently. He had accepted from the first arrest that he was dying, and actively tried to bring that about.

This Sydney hospital is well known for its high level of "bed to bench" research. Something Prime Minister Rudd has rewarded financially at a time when NSW health is in debt to suppliers of services right across NSW. As of September 2009 (ABC News 14 September 2009) NSW Health is in debt to suppliers for over \$70million and suppliers are considering stopping supplies of bandages and other things, yet there is a billion dollars for research on top of what they already have.

On 10 March 2009 the Sydney Daily Telegraph reported:

Prime Minister Kevin Rudd is to approve a \$1 billion rollout for a network of medical research units across Sydney in what would make the city the world's research capital.

A mass bailout of the hospital system now appears to be unlikely with the PM said to be unwilling to throw money at the NSW Government to fix its Budget problems.

Instead, sources in Canberra claim that Mr Rudd was "disposed" to a \$1 billion submission from NSW Health for funding of eight medical research institutes across Sydney.

(www.news.com.au/dailytelegraph/story/0,22049,25163301-5005941,00.html).

Don's agitation was often accompanied by hallucinations and I would see him follow things around the roof of the ward, and fixate on something as if it was moving or alive. He was obviously terrified of whatever he was seeing – always in the same area of the room. I would quietly pat his shoulder, say his name softly and he would look at me and drop his shoulders in relief. For that moment he would be not seeing anything but my face or Melissa's but soon he would be back in the nightmare world he alone could see. There were weeks of this. It was especially appalling for him and for those who visited. There was nothing we could do to stop it. But during those days when I sat with him with my hand under his neck, warm and touching, he and I knew. There was a lot of very deep and lucid communication. Remembering the days spent like this brings tears. I wonder to myself, why didn't I just stamp my foot and demand to see the head of ICU and ask that he go to Don during his good hours and ask Don what he wanted? How many nights have I dreamt that this is what I did? I don't even recognise the 'me' that was there at times. Having to come to terms with this has been the hardest internal battle I have ever fought. Writing this now, my heart breaks open again for Don, Melissa, Alison and for myself. I have learned to deal with shocking memories which crawl out of my brain like maggots. Going to sleep each night, I pray it will be light when I wake. The long nights bring too much thought and suffering. This is the legacy I have been left with. I have no doubt that my girls also suffer. But I hope not to this degree.

Much of the time, the tube in Don's mouth was tied around the back of his head to hold it in position. The edges of his mouth were red raw and sore at times and the skin of his mouth was all sloughing away from the Candida Albicans (or thrush) infection which was throughout his digestive system as a result of the very strong antibiotics he was on.

The only tooth left in the front of Don's mouth had been knocked out of position at the time of the first respiratory arrest, presumably when doing the emergency ventilation, and left in a sharp dagger in the front of his mouth. (Don had lost all his other teeth due to the medications he was on, and had false teeth.) He lacerated his lips and fingers from this razor sharp, broken tooth. His body became so swollen it was horrible to see, the skin stretched so tight with excess fluid I thought it would just split open. Don's reaction to unrelieved pain was Autonomic Dysreflexia, and

one blood pressure reading I noticed was 214/110, which for a quadriplegic is shocking as they sit usually on 80/50. Don felt intense pain internally, and with all the swelling he had to be suffering. Although he'd only had a moderate right-sided pleural effusion when he left our local hospital, the pleural lining of both lungs now had fluid in them. But it was not just fluid; they were also full of infection, which was blood-tinged from the pneumonia and the MRSA. His lungs crackedled with these infections.



Don's disastrous treatment – which I have only touched upon up until now, just the tip of the iceberg – was a horror story. It plays almost continually in my mind. Even when sitting around a table with people, there is little ease from these pictures. It feels like I've become two different people. One, the public face, is trying to hold calm. The other is private, one I can't share. This person will sit on the floor howling with inconsolable grief. Not because of Don's death. We all die. It's the manner of that death. At present I feel so terribly damaged, as if I'll never really be myself again. Occasionally I'll find something so funny that I start to laugh out loud like I used to do so often. More often than not, the sound of myself laughing in the quietness brings tears and I end up a mess. If I found something funny or interesting, I'd come tearing to wherever Don was already talking or laughing and he'd listen and be interested or tell me where to go in his unique style. Sometimes we laughed so long together we'd have to try not to look at each other because it would set us off again.

I feel emotionally wrecked. Just wrecked.

Not one bit of this would have happened if Don had received the right treatment when he went to Sydney and been accompanied by his scans and X-rays and comprehensive discharge notes. And why include the word 'Pleurodesis' in discharge papers when the only doctor to raise that issue had never seen Don and had no idea of what state he was in? It's all one huge mess. It feels as if they murdered him, except that would imply intent.

Don's death was the result of people being disconnected and disorganised, I realise, and not intentional. But once the damage had been done for whatever reasons, it appeared that those who knew covered up what had happened and extended his suffering with extreme lack of care and cruelty, not intentional I realise but it still caused Don such a level of suffering it has to be mentioned.

Don's Condition Deteriorates

On that first morning in ICU, at the time all these medical notes were being written up, I was in the waiting room pacing, sick to my stomach, shaking, furious and cold as ice. Melissa had arrived at some point and we were left alone in the ramshackle and silent waiting room. I had not been able to see Don and was sick with worry as nobody explained anything about what had happened, apart from a brief sentence about the respiratory arrest. We were not allowed to go in to see Don until a couple of hours had passed.

I saw the admitting specialist briefly, very early that morning – as I recall, that was the last time I saw Don's admitting specialist – but was made none the wiser as to the cause of what had happened, even though at 7am a member of his team wrote: 'Events noted. Respiratory failure with low inflammatory markers. ?alcal reaction'. I cannot read the rest. This is the same doctor who had earlier seen Don in Spinal and said he was 'unconcerned' – despite the fact it was obvious – to me at least – that he was in serious trouble. I just did not know what the problem was. Once Don was in ICU, why didn't these doctors tell me what they suspected and recorded in the medical notes? I should have been informed from then on, every time I asked and with every change that happened. But I was to be kept in ignorance, relying solely on the excellent research of Melissa and Alison, and my sister Veronica. Alison spent hours every day following things up and many of the research papers listed in the back of this book come from her endeavours.

We found out for ourselves what caused the respiratory arrest and ARDS, but even then no one would admit it to us. What we discovered ourselves was spot on and the hospital notes support what we found out. In Australia today, what legal requirements are there on doctors to honestly answer questions from patients and their families? We were asking the right questions, as it turned out but from the very beginning they neglected to keep us informed. The doctors also keep mentioning 'recurrent' pleural effusion, because this helped justify the original decision to do a Pleurodesis. In the family's opinion, this term was incorrect. But once on Don's records, it became reality; and was the beginning of the tragedy that unfolded.

On the 'Record of Medical Emergency Event', Don's '+ + agitation' is noted. It had been noted for days before by me and passed onto nurses and the doctor. It was, I now know, caused by the build up of carbon dioxide in his system. They should have known this, all of them. There are no excuses for this carelessness and disregard. They ignored all my warnings and all the signs clearly before their eyes and for a doctor to say he was 'unconcerned' is, in my view, deplorable. Don was terrified, and they treated him like an idiot.

For the five weeks Don was in ICU, he had his arms restrained, a situation that was distressing for him and for us. He wasn't able to communicate much at all, apart from nodding and shaking his head, as the tubes down his throat stopped him being able to speak properly. Also in the first days his throat became raw and the tubes had to be tied tightly across his mouth like a horse's bit and tightly round

the back of his neck. Ironically, someone organized for a speech pathologist to see Don two days before he died, after he had been in ICU unable to communicate properly for five weeks.

With the tubes tied so tightly, the corners of Don's mouth were very sore, a problem that was addressed or not depending which nurse was on. Sometimes I would ask a nurse to loosen the tubing off because it was cruelly biting into his face, and it was distressing him and us. Don wanted those bloody tubes out; he wanted to be let go even at this early stage. He and I knew that any major lung injury was fatal for him. As painful as it is to express this thought, I felt from the early days in ICU that Don should have been allowed to die without prolonging his suffering. I was in the awful situation of loving him deeply, of maybe holding out a small sliver of hope the doctors might be able to fix up the damage they'd done, but knowing in my heart it was only a matter of time and he would not survive. I knew there was no point in making him suffer so much when there was no possibility of prolonging his life and easing his suffering. Had any Spinal Unit specialists deigned to attend Don, they would have recognised this from the beginning. This Spinal Unit was, as barrister Peter Garling SC said during an inquiry he later conducted into NSW's public hospitals, was Don's '*home hospital*', and Mr Garling expressed dismay that specialists from this Unit would not have attended one of their own patients. This is all recorded in the transcript of that Inquiry.

The ICU and Cardiothoracic doctors' explanations were so obscure; we never got straight answers on anything we asked. I know Don and I were in a strange, elongated state of shock. For me it was as if I was walking through pea soup and my usually strong will had been taken away. I felt pulled by whichever 'expert' was at his bedside; all of them seemed to be telling us different things. Don was very agitated and very frustrated at having his arms constantly tied to the bed. Lucky we did not know how long this was to last.

It is curious to note that five weeks later, when Don was told he could go home to die, his agitation lessened and he became peaceful and very lucid. I believe this was probably a combination of them stopping many medications, and the fact he was achieving his aim. He wanted to come home, even if it meant he was going to die but he could not talk past the ventilator, and as a Quadriplegic could not write. He had trouble even pointing as his hands were permanently curled up. It disturbs me to think I failed him in his wishes. If he had not been so disabled, I would have had no qualms about asking that his wishes concerning ventilation be respected. As it was though, I could not even ask. Were I to suggest, talking with ICU doctors and Don in those early days about taking the ventilator away, there would have been suspicion of my motives. When someone is disabled, most people just assume – there's that word 'assume' again – that it's all suffering. But life is as rich as you allow it to be, and ours was very rich. From what I see of many able-bodied couples around me, their lives seem much poorer than ours and they always seem to have complaints. But then, I must not assume either.

So I said nothing, and hoped in my head. But my heart knew the truth. During all those weeks of Don's infection-filled suffering, not once did he show me anything but love and patience. He was more caring for my welfare than his own.

I know and experienced these things. I have to deal with the issue that I should have been stronger in this. There were our two daughters to consider also and I really never spoke to them properly about these things at that time. Although they are adults, it was too much. We'd all had too much to bear, and from the outside world there was much too little compassion. There was, basically, no compassion at all, apart from the hospital chaplain. She was like a lodestone at times and really the only friendly face among the staff, apart from the very occasional wardman or woman, or nurse or a doctor's fleeting comprehension. She never preached or pushed. She was just there. Many days, her presence was the only compassion I felt apart from the deep well of love and empathy that poured out to me from the wonderful heart of my dying husband.

As for most of us relatives and friends of those patients in ICU, we were immured in our own suffering in the gloomy waiting room. Just as an aside, during the whole time we were there, the public phone in that waiting room full of people who were losing or could lose loved ones in the near future did not work. That bloody phone was out of order the whole time. So those who didn't have a mobile phone had to leave the floor and go down in the lifts to the ground floor to ring friends and relatives. It was unbelievable. Some people there in that room were obviously very poor. Some had family with them sometimes, some had a few family all the time, and some had lots of family. Some were always alone. I was one of the 'family sometimes' ones. My heart broke for the lonely ones who never had anybody to share their burden. The days I was alone were horrible. Cold and raw. But some of those people never had anybody at all. It's over for me now, but no doubt right at this moment it's exactly the same in that room for people just like me and my heart prays for them to have ease.

With his arms strapped down and his mouth gagged and tied and with all that was going on, Don was very frustrated, and it always gave me pleasure to untie his hands while I was with him. Melissa said at his funeral:

I remember when Dad's arms were tied with restraints. Mum and I untied them and he stretched out his arms like he was going to fly away. I said jokingly, "You're free!", and he laughed and smiled. It was the most beautiful smile. So I hope he is free and still has that beautiful smile that I'll never forget.

Just to remember that smile still brings tears to my eyes. Don was blessed with a smile that made you feel as if something beautiful had been bestowed. That same smile charmed me the day we met in early September 1972. He was not the world's most tactful person. He called a spade a spade and did not suffer fools gladly, but his love was like a deep pool and he had a great humility in giving it, if that makes sense. No matter what he had said or done – and he said and did plenty – that smile would always be there like a blessing.

It was obvious some doctors and nurses felt that because Don was quadriplegic, he must have been brain-damaged. Often, this was revealed by the way they talked to him just a little too loudly. Other times, they wouldn't talk directly to him but to me instead, even when he was fully aware and watching. I was amused, as was Don, at how many ICU nurses wondered why he could not move his legs. There were nurses who could not be understood, as their grasp of English was so bad. There

were nurses who were patronising and who, once they had it in their heads that he was a quadriplegic and 'agitated', decided he must also be stupid. Their mistake – but Don suffered for that.

I am unsure of all the medications he was on, as the charts are hard for me to understand. But I know that Don's medications should never have been stopped 'cold turkey', but only gradually. For years he had been taking heavy-duty, opiate-based painkillers. It seemed to me that even in ICU, the drugs were shuffled about a lot. I need someone who can follow this to explain to me what happened.

I believe there were multiple reasons for his agitation and why he hallucinated. One was the lack of oxygen, but also, if his usual drugs were stopped for even half a day, he would have severe side effects and major withdrawal symptoms. I read in the notes that even on the first day they record him as being '+++ agitated and pupils unequal'. Even intubated he was taking 45–65 breaths per minute. He was clearly trying to get more air than the ventilation tube was able to deliver. This alone would have been dreadfully uncomfortable and distressing.

It's hard to write up a day-by-day account of Don's time in ICU. The five weeks became my world. Nothing existed outside. At times I even forgot what day it was. Many days were so terrible, I recall not feeling, just doing. It was like I was separate from my feelings. I would feel my face – numb. I had trouble holding my eyes together. One of them wanders when I'm very tired. I remember Alison saying how strange I looked. Thank God that I was raised in a home in which the individual mattered and life was sacred. Thank God that I lived with a man and had children who feel the same way. Without this common thread holding us together, I don't know how I would have handled things, then or now.

Though Don had been a quadriplegic since 1982, for 25 years he had been able to breathe unaided. It was only after the Pleurodesis operation that Don could never again breathe without the aid of a machine. If that operation had not been done, he and his special smile could be with us now.

It was on Don's second day in ICU that he first bit through his ventilator tube. There are a few reasons why he did this, I feel. Extreme agitation and tube intolerance; pain from the broken tooth and from its being a sharp spike in the front of his mouth; and because he wanted the tube out so he could die and was prepared to suffer anything to do this.

Recently, I was looking in a bedroom cupboard and found a hospital specimen container. Inside was the part of the tooth that was broken off. It must have been sent home with Don, but in all the confusion after his death somehow it got pushed to the back of the cupboard. I sat on the floor (a favourite place for a good cry) and wept. His poor rotten broken tooth. At first I was so angry. What sort of reasoning was there in the person who sent a dying man home with a broken bit of tooth? But after I settled down, I figured it was a part of him. So I sealed it in a little pouch and put it somewhere safe.

It was noted after Don's first extubation that he was 'confused and disorientated'. These were serious indicators before a respiratory arrest. On seeing these symptoms, he should have immediately been put back on the ventilator breathing machine, so as to prevent the suffering that came with the build up of carbon

dioxide. The damage to Don's lungs was so great and irreversible – known, but not admitted to us, by the doctors – that he couldn't breathe unaided. Unless carbon dioxide was expelled, it would poison his whole body, causing a respiratory arrest. Five or so times during Don's stay in ICU, he was taken off the ventilator to see if he could breathe normally. He never could; his lung tissue was so badly damaged his lungs no longer worked. So although I understood why doctors tried to see if he could breathe by himself, the moment he showed he couldn't by his shallow rapid breathing and confusion, he should have been reintubated. Every time they removed the ventilator, they waited far too long to put him back on – hours and hours (at one time Don suffered this for ten hours) when it should have been just minutes. Each time, his lungs were damaged even more.

Each time they removed the ventilator, they continued to leave it until Don's distress was terrible to watch before they would reintubate. He was given nothing to ease this suffering and I can still see his terrorised wide-eyed appeals for relief. It sits behind my eyes as I go about my daily life. It is always there. A shocking legacy. But how much worse was it for my lovely husband? He suffered so much. Too much and all needlessly. During these early days, Melissa and Alison, Chris and Andrew, my sister Veronica, Don's nephew Rod Collins and a very dear friend, Neil Thrift, visited and all saw what I saw. Veronica and Rod had made it down from Queensland that first day, dropping everything to come. When Neil came in he gave Don a big kiss on his forehead and said, "I hope they won't think we're poofs or something", and Don's face broke out into the widest and most beautiful grin ever. He smiled for ages after that and I will be eternally grateful for Neil for this. It was one of the few truly beautiful things during that nightmarish time. I can still see Don's smile beginning and just getting wider and wider. His eyes shone. Neil had been fighting cancer himself but made the effort to see Don twice, coming all the way from home. Sadly, he recently passed away; another one of the good ones gone.

On 17 April, we watched Don go through exactly the same symptoms I had seen in the Spinal ward as the ICU staff attempted to extubate him. His breaths were coming faster and he was not making much sense. They had Don on a mask with nasal prongs. Unfortunate and stupid of them again, as he mouth-breathed, but they did what they did as usual with no common sense or basic medical knowledge in evidence. Alison was able to have the last real conversation she ever was to have with Don that afternoon, on the telephone. He told her many times how much he loved her and kept repeating that when he bit down on the tube it tasted awful. They talked for some time. Alison said he was a bit muddled, and that he sang to her over the phone. She came up from Melbourne the next day. She'd been sick for some years and Don did not want her to stay too long because he was so afraid she would pick up MRSA or some other bug and go backwards. It was most important to him and he conveyed this to us easily.

Physiotherapy began to suction small amounts of secretions from Don's lungs – not a good sign, as he had not had this when he came to hospital. They also detected a moderate effusion in the pleural lining of his left lung, which had had been entirely fluid-free before Don arrived at the city hospital. None of this was explained, it just all happened around us. As mentioned, there was one nurse for each patient in ICU, but we were only told useful information if and when we saw

things happening and asked precisely the right questions. Most of the time, even then we didn't get the full truth. Many medical staff appeared to have a culture of not telling us anything at all.

Veronica, Neil and I were visiting all that day. I have trouble deciphering the nursing notes for 17 April, but it was a dreadful day. They put a couple of different masks on Don as he was struggling post-extubation. I warned them all day long that I was seeing exactly what I saw in Spinal before Don's respiratory arrest and it was getting worse more quickly. Of course it is not in the doctors' or nurses' notes, but my concerns were fobbed off, as usual. Only the physiotherapist noted my concerns word for word. The mask Don was on finally covered his whole face and head. I watched my husband struggle and struggle, panting faster and faster, his tongue starting to go in and out as it did in Spinal, but more dramatically and with increasing speed. Don was so very frightened and although delirious, he knew what was happening because his eyes told us so. They were like the eyes of terrified cattle.

I became quite frantic as the afternoon drew on. When we noticed on the monitor that his breathing rate had risen to 50 per minute and mentioned this to the nurse on duty, she got angry with us and said, "What are you worrying about?" And then, inexplicably, she either turned the display panel away, so we couldn't see it, or off. Veronica remembers it being turned off, and she is a renal dialysis nurse of 25 years experience. None of this is written down in the progress notes. That specialised ICU nurse, with only the one patient to care for, then delivered this bit of professional advice to allay our concerns, which by then had become terror. She said the reason his tongue was going in and out rapidly, lizard-like and harsh, was because: "He is trying to talk".

We had to stand there helplessly and watch as Don began to go into full respiratory arrest. The nurse gave him a cursory glance. She could barely see his face because the full face mask was so full of condensation, but with his tongue extended as far as it could go she said, again: "I think he is trying to talk." If it hadn't been a human being on that bed, it would have been like some black comedy.

We gave up on Don's nurse and in panic called the nurse looking after the patient next to us. None of the lead-up to this respiratory arrest was noted. They never wrote down their failures to act after being warned. All the nurse wrote was: 'Essentially stable', but shortly after this notes: 'Hallucinating, now difficult to rouse'. The alarm was hit and everyone rushed to his side. The failure to act after being warned was not mentioned. This happened frequently.

I feel sick to my stomach when I think about that day and how Don was treated. It was not necessary that he had to go through this frightening and dreadful experience yet again. His nurse should have seen he was not coping, contacted the doctor and reintubated Don at the first sign he was struggling. But they pushed on, taking him to the edge of respiratory arrest yet again. Why? For what purpose? The cold detachment of many around Don shocked me. There is something very wrong inside that hospital and the health system in general. Had they watched him more closely and taken my warnings seriously, it would have been clear he was unable to cope off the ventilator. But

we were just hustled out and told nothing. When we returned after the emergency reintubation, Don was worn out and disorientated again.

Having to be reintubated was a disaster for Don, with ominous meanings. Yet when it was done, his oxygen saturation level on the monitor showed at 100% – meaning his lungs were functioning supposedly perfectly. So the instruments obviously weren't revealing Don's critical breathing difficulties. I said to a young female Asian doctor: "They have to stop looking at the instruments and look at Don – he's really struggling." She agreed with me and was very compassionate. I can still remember what she looked like, and would like to name her for her compassion, but as with all staff, she wore no name badge.

Another time, Don had to be reintubated after yet another futile attempt to wean him off the ventilator. The nurse noted just before reintubation: 'Patient initially alert and orientated, responding appropriately to time place and person. Slowly deteriorating neurologically, increasingly agitated, disorientated to time and place, unresponsive after 11.50am, SATs at 93–99%'. So poor Don became unresponsive again, while being watched by ICU doctors and nurses. He was allowed to come to the edge of yet another respiratory arrest, in front of them. If you have never witnessed or had an untreated respiratory arrest, let me tell you its onset and the suffering involved is dreadful. I am puzzled and angry that ICU staff repeatedly let him get to the point of respiratory arrest before acting. They were actually with him on this occasion, trying to reinsert an arterial line. We had been sent out, frantic with worry. It just makes no sense at all.

During this time, the nursing notes mention thick secretions and also the physiotherapy notes mention 'creamy thick blood-stained secretions'. Don had almost another four weeks of this to go.

At 10pm on 18 April, I rang the hospital and spoke to Don's nurse, who told me his left lung's pleural lining was to be drained the next day because, by now, it had begun to fill up with fluid. It was clear and healthy when we had arrived at the Hospital. I expressed my disappointment at not being told this earlier. The nurse said doctors only made the decision at 9pm, but the notes show 6.50pm, and I was always contactable. I would, in fact, only have been beginning to leave for the night at that time. Why would they not think to advise me? Would they have told me if I hadn't rung that night? I doubt it. It would have been just before it happened.

The illegibility of most of nurses' and doctors' notes makes me wonder how they could read each other's writing accurately, and it makes me wonder how many times serious mistakes occur because of illegible handwriting?

Alison wrote down some observations of her own at this time. She noted:

Thursday 19th April: Dad was aware in morning after a toothbrush from the nurse. He was nodding and smiling at Lissy, Mum and me. He nodded that we are a special family and had a chuckle at the "bog eyes" joke. His eyes weren't properly awake – kind of flicked open and shut. He was tired all afternoon. Sedative I believe was given so he wouldn't chew through the tube. Ventilator turned down so he could initiate his breaths and strengthen his lungs. Thurs morning left lung found to be filled with fluid. Drained this morning 800mls plus a draining tube put in. He has really bad fluid retention. He knew I was there and

knew which side Lis and I were on with his eyes closed as when Mum said "I think Ali needs a hit", he flicked his arm to the left and then to the right when told "Lissy needs a hit". It was presumed that he had brain damage but today proved to me that he is still Dad. He had so much understanding and correct responses. Spoke to the ICU doctor with Veronica, Mum, Melissa and me. It was uninformative and although we asked he kept saying he had no answers.

With our family all gathered, the ICU doctor held a family conference. Finally it seemed someone was going to tell us what had happened and where to from here. We later realised that at the time, the ICU doctor knew exactly what had happened to Don and why. After Don's death I found where he had written it and marked it prominently in medical records. But when Melissa, Alison, Veronica and I tried to get information from him that day, he told us nothing. The conference was not helpful, and worse, took us away from time with Don. It was just theatre. Alison wrote at the time that when the ICU doctor asked us to ask him questions we did, but he said he had no answers. To each of our questions, instead of replying, he would say in a sing-song voice: "That's a good question."

Here we were, desperate to find out what had caused Don's arrest and why he couldn't breathe by himself. The doctor had the direct chance to tell us what he knew, but even when asked directly, he refused to tell us the truth. Alison remembers, "He asked if we had any questions and Melissa began asking a few. His reply to each of one of them was, 'That's a good question but I don't know the answer, do you have any other questions?' It was said in a jovial sounding voice like it was something to laugh at or was funny in some way. I was pretty angry and I said, 'Well, what can you tell us?' I think that stopped him dead, the smart arse bastard; I just wanted to slap him! He asked us what Dad's life was like at home and what he did with his time. He also asked if he would be able to live that life with a trachea in place or on a ventilator, and also had Don spoken of his thoughts of being kept alive on a ventilator? Mum said they had actually spoken of it and Dad had said he hadn't wanted to be kept alive on one."

The ICU doctor wrote in his notes what he suspected had caused Don's respiratory arrest and failure to come off the ventilator. 'Mr. Mackay has deteriorated post-extubation today. Again he has developed delirium and [illegible] respiratory failure. The cause of his illness is not clear to me; I suspect his quadriplegia has left him marginal respiratory reserve that has rendered him incapable of ventilating after his Pleurodesis. His CO2 has gone ++ [illegible], have reintubated him.' I have to thank The ICU doctor for ensuring that these comments could not be missed among the notes by marking them so prominently, but he should have told us what he suspected caused the respiratory failure and inability to be extubated when we asked him directly. We suspected the same, but no one ever explained to us what had happened. Again we had to do our own research. Yet weren't we supposed to be kept fully informed?

Only recently, Alison told me about an event which shows the attitude of one ICU nurse. Alison noticed that Don's blood pressure reading was dangerously high, and told the nurse. Both Melissa and Alison knew the dangers of Autonomic Dysreflexia, and had for years all through their childhood and now as adults. Yet this nurse argued with Alison. When Alison would not back down

because she was so worried about her dad, the nurse turned off the screen so Alison could no longer see it.

The medical notes state 'right lung exudate fluid and left lung transudate fluid'. Only after our own research have I begun to understand, courtesy of the internet, what these words mean. 'Transudative pleural effusions are caused by systemic factors that alter the balance of the formation and absorption of pleural fluid (e.g. left ventricular failure, pulmonary embolism, and cirrhosis), while exudative pleural effusions are caused by alterations in local factors that influence the formation and absorption of pleural fluid (e.g. bacterial pneumonia, cancer, and viral infection).' Don's right lung pleural exudate in the local hospital was borderline.

The doctors' notes also state '?Talc reaction'. Despite all their testing, they had still found no cause for the original effusion, and never did, but they behaved the whole time as though they were on the verge of some great discovery. After his first arrest, the simple fact was that Don was being artificially kept alive and had no hope of surviving the collapse of both his lungs, most likely caused by extreme suctioning and also the inflammatory response following the failed Pleurodesis. Don and I both knew that any single bad event in his lungs meant certain death because of quadriplegia. He was left with multiple bad events.

The notes record, 'disordered breathing'. Of course it would be disordered, knowing as we now do the full extent of the damage caused by that Pleurodesis. They also admit 'poor respiratory reserve related to C5 quad and dependent on diaphragm.' If they understood this, why sit Don up in his wheelchair in Spinal when he was having visible trouble breathing? Again there seems to be a lack of continuity and connection in their understanding of quadriplegic breathing.

One of the admitting specialist's team recorded that Don had dyspnoea [breathing difficulties] 'since 2005'. Where that statement came from is anybody's guess. It was only late in 2006 that we noticed any breathing difficulties, and Don's local doctor couldn't see anything when he examined Don in January 2007. The admitting specialist's offsider also says in the notes, 'Post Op confusion', which I'd mentioned to nurses in the two days before Don's first respiratory arrest, but was ignored. Their team member remember, was 'unconcerned'. This doctor then goes on to note: 'I suspect he has had acute lung injury (unsure of symbol used here, could be 'following' or 'as result of') Pleurodesis with + effusions as a result. With his C5/C6 spinal injury he almost certainly has impaired respiratory mechanics/ fluid overload may have been potentiated by fluid input. Autonomic Dysreflexia has contributed to difficult BP management. Am uncertain as to cause of R exudate etc. A spinal physician's input is needed.'

While Don was in his last weeks in ICU, it was this doctor, if I have the name right, who slogged it out with me by denying the cause of Don's condition when I asked him. Yet his notes prove he knew all along what had happened.

Infections Out of Control

Don had been moved from one part of ICU to another because MRSA had been discovered there. The physio now reports 'blood-stained sputum'. It was 21 April 2007 – only 10 days since Don entered the Sydney hospital with just a moderate amount of fluid in his right lung's pleural lining. And so the dreadful days began to merge into one another. Each day as bad as, if not worse than, the one before. Only 11 days since he went down the street with me and won \$600 at the TAB and had a haircut. We had lunch that day in town. Only a little over a week.

I read the nursing notes for 21 April where the nurse writes, 'Family aware of patient's condition and (unreadable) in ICU'. They may have assumed this because we were in front of him and seeing his suffering. However, we only knew what we could find out for ourselves. Very little information was offered and the communication was deplorable. All I ever seemed to get was that they still hadn't identified any cause for the original right pleural effusion. We all knew what caused the huge amount now in the left lung.

According to the doctors' own notes, at this stage Cardiothoracic and ICU doctors knew about the side effects of failed Pleurodesis, and Acute Respiratory Distress Syndrome, and all of that. But we were never once told any of this. Even if they only suspected this was the problem, we should have been told. They knew. I was, and am, so intensely angry with them. Then, I felt as if I was swallowing screams inside myself. I feel like this still. Sometimes even now, driving along by myself, this internal scream comes out like an awful moan straight from the guts or heart. Sometimes I feel sick and would like to vomit but it doesn't happen. I know the girls feel like this too and I try not to lay too much on them, but sometimes we have to talk about it. There is a strange sort of bonding among those of us who saw and experienced what was done to Don in that disgraceful hospital.

On the morning of 22 April, Don was again extubated, then again reintubated because of his dreadful distress and struggle. And on it went. On it goes as if it's still happening. This testament is my way of helping my girls and myself I hope, begin the mending of our hearts. I know Don would not want us to be grieving as we are. But I also know that if what was done to him had been done to me, I would not want to be the offending doctors and nurses. What he would do to them wouldn't be legal. He was sort of old fashioned like that.

On 22 April, an ICU doctor notes, '*I have spoken with Mrs Mackay and sister and updated them. He is in trouble with respiratory failure. I have answered all their questions.*' Yet we were never told about the inflammatory response to the Pleurodesis, even though that doctor again had the opportunity to tell us at that point. Lying by the omission of known facts, when a patient's life is so threatened, has to be some sort of offence – surely? Are doctors the only professionals who can blunder about, making mistakes, obfuscating facts and nobody anywhere will do anything about it? In NSW, as I have learnt, there are few if any avenues for justice for those who are killed or injured by medical mistakes. Most people don't want to sue, but they

have a right to justice. I just wish more insiders would break their silence and have the humanity and courage to reveal the truth.

A common attitude held by many doctors is that they have a legal right to refuse a treatment even though it will do no harm and has a chance of improving, even if only slightly, a patient's condition. We had asked an ICU doctor to allow Don to have an intravenous drip of Vitamin C at 15,000mgs, which many doctors say can help the immune system. We had medical advice on this and on the recommended amount and delivery. It would have been easy to do, as Don was on a permanent drip anyway. But she would not allow Vitamin C at any effective level, saying it could cause kidney stones. This, even though the ICU pharmacist said it was fine and that supplies were available, as long as a doctor authorised it. We are still angry we could not make this happen. This doctor would allow only 1,000mgs a day, taken orally, which was useless for three reasons: the dose was a tiny 1/15th of that recommended; the antibiotics Don was on had caused *Candida Albicans* which had invaded his digestive system, allowing little absorption of nutrients via his stomach; and it was in pill form instead of liquid. At home Don always took 3,000–4,000mgs of Vitamin C daily plus other supplements and had done since 1982, with no kidney stones or other ill effects. It appears there is a great reluctance among many doctors to use any substance not patented by a pharmaceutical company. These days, many people in remission from cancer or undergoing chemotherapy or radiotherapy have frequent intravenous Vitamin C injections and get great relief from many of the extreme side effects of chemotherapy. Alison had intravenous Vitamin C treatment for about two years when her system collapsed after becoming seriously ill, and that treatment certainly didn't cause her any kidney stones.

We also mentioned to the doctors a cortisone treatment for ARDS which is in the medical literature and which can turn the condition around in many cases but this too was denied. We all knew Don's outlook was grim, but I would like it explained to me why he was denied treatments which might have given him just a sliver of a chance, or at least lessened his suffering. The treatment of Don, apart from a few exceptional nurses and doctors who forever have my thanks, made his suffering much worse.

Often through the weeks, the nurses and physios especially reported that Don was 'not following commands'; generally on these days he was very agitated, and I could see the distress he was in. He appeared to be fading in and out of hallucinations at times, as if he could see things we could not see, but then would just as suddenly snap back to full consciousness. This was dreadful for a man who had always had so much mental control. The reasons for this have never been explained, but as mentioned, Don became totally lucid once all extra drugs and treatments were stopped. This issue needs review, because it caused him such distress and robbed us of so much time together. I can't read the notes about the stopping and starting of Don's medications, but if it was anything like the mistakes made in Spinal, there must have been errors.

On 24 April, only twelve days after admittance, one of the admitting specialist's team noted a third failed extubation and also Don's *'marginal resp. reserve/ diaphragm dependant and v weak resp muscles which make wean from ventilator v*

difficult agree trach seems v likely. What was interesting there is that he mentioned Don's breathing being 'diaphragm dependant'. It always was, as one would have thought the admitting specialist would perhaps have noted even before surgery, or as the 'unconcerned' specialist might have noted before sitting Don up in the wheelchair? Why didn't they talk to us about any of this? It appeared that the knowledge was meant for the doctors alone, while the patient and relatives were kept in the dark?

There is another issue noted here, along with Don's quad breathing: 'V weak resp(iratory) muscles.' Again, as a quadriplegic, Don always had these and over the years they had become much weaker. Another compelling reason not to perform a Pleurodesis. Yet according to the hospital records, the spinal specialists in that place were just not interested in Don's proposed course of treatment at all, even though he was a quadriplegic and this hospital was his 'home' Spinal Unit, the only one he had attended in 25 years. It is clear from the notes that both the cardiothoracic and Intensive Care specialists were trying to get spinal specialists involved. That is, they were correctly trying to get Spinal Unit specialists involved in his care, as should have occurred right from the beginning – but without success.

Again, as with Don's treatment from that January day when he first saw his doctor about breathing difficulties, every time a correct turn could have been taken in his treatment, with bizarre regularity and almost without exception wrong decisions were made, right up until the end and even after when they rang to see how the patient was going after his "discharge". Don had been already buried by this time. Obviously nobody bothered to read the discharge notes

On 24 April, a Resident Medical Officer, or RMO, notes, in relation to a so-called 'conference' we had with the cardiothoracic registrar who was the interviewing specialist (the doctor who originally signed Don up for the Pleurodesis after seeing him for a few minutes on the night he arrived): *'Family concerned about sudden deterioration in Donald's condition after Pleurodesis, compared to his pre-admission state. They have investigated on the internet about VATS Pleurodesis and were concerned that his current inability to stay off the ventilator was related to an allergic reaction to the talc and that this would need treatment.'*

The registrar explained that the medical consensus was Don had had an allergic reaction, which he said had been "treated". It was not explained to us when and how this reaction was treated. The registrar also said Don's state at that point was not likely to be related to the allergy itself. If this makes sense to any but the Health Care Complaints Commission, which declared all treatment "acceptable", please tell me what planet I am now living on.

We were very unsatisfied with this conference with the interviewing specialist and aware of the disapproving attitude the medical staff had towards us doing our own research. But we were forced to, because no one would be straight with us. Even at this stage, doctors were fudging about and making unclear statements, not having the guts to tell us exactly what happened, as they did in the notes. I want this sort of behaviour to be investigated, as it is and was our right to be told exactly what all the doctors were writing in the progress notes. But instead, we just got little bits of information which were well nigh useless. Everything we found out on the internet, even one of the admitting specialist's

own letters to a medical journal, was exactly what happened and the doctors' progress notes back this up.

It's pretty obvious though why doctors don't want patients and their relatives digging around on the internet, doing their own research. We found, for example, a 2004 letter to the editor of the *American Journal of Respiratory and Critical Care Medicine*, in which the admitting specialist and two colleagues from the hospital state: "*We conclude that... the severe local inflammatory reaction incited by talc may be sufficient to cause a fatal systemic response.*"



Don in the first ward in ICU at the city hospital. This was taken by my sister (with my permission) to be emailed to some relatives who did not believe how ill Don was. I ensured Don was asleep – and this photo is very disturbing as he was dying here but still had five weeks of torturous suffering to deal with after this.



“Study of a man shouting”

Charcoal on paper,

Michelangelo Buonarroti

Gabinetto Dei Disegni E Stampe, Uffizi, Florence, Italy.

Melissa saw this in a shop window in Sydney and recognised that this was exactly how her beloved dad would have felt – as she said “scared, horrified, angry, desperate, unbelieving and full of terror”.

This image is how we all feel Don felt yet could not express – it haunts us all.

Melissa bought this print and has it on her wall – it saddens me to understand the damage she has suffered.



*"The Temptation of St. Anthony"
Oil on panel,
Matthias Grünewald*

Musée d'Unterlinden, Colmer, France.

*My sister Veronica – a long time
Renal Dialysis Specialist nurse
stated that to witness being inside the
ICU at the city hospital Don was in was
like being inside this mad painting with
Don as the central character being
tortured and abused by the demons
and imps.*



*Above:
My eldest sister Veronica,
Melissa and my dearest
friend Carmel Lewis
launching our petition.*



*Pictured Left:
Our display outside
NSW Parliament House
1st April, 2008.*



My street stand while collecting petition signatures outside the Commonwealth Bank in Port Macquarie. Photo Courtesy – Port Macquarie News.



Handing the NSW Nationals leader, Andrew Stoner, the petition for presentation to the NSW Parliament.

The Pod Room

As he knew was all too likely, Don was infected by MRSA while in the Sydney hospital. At first this was present in his arterial line, which was used mainly to draw bloods for the hospital's 'NICE-SUGAR' research. Those initials stand for Normoglycaemia in Intensive Care Evaluation – Survival Using Glucose Algorithm Regulation. Run in Australia by the George Institute, more than 6,000 ICU patients signed up to, or were signed up for, this study, the results of which have now been published. Various bodies have expressed concern about this study's impact on seriously ill patients, including this statement:

Joint Statement on the NICE-SUGAR Study on Intensive Vs Conventional Glucose Control in Critically Ill Patients

The American Diabetes Association (ADA) and the American Association of Clinical Endocrinologists (AACE) maintain that the findings of the Normoglycemia in Intensive Care Evaluation-Survival Using Glucose Algorithm Regulation (NICE-SUGAR) study should NOT lead to an abandonment of the concept of good glucose management in the hospital setting. Uncontrolled high blood glucose can lead to serious problems for hospitalized patients, such as dehydration and increased propensity to infection.

Results from the study indicate that critically ill patients treated in the intensive glucose control group were 14% more likely to die compared to critically ill patients in the conventional control group.

More than 6,100 patients with hyperglycaemia in critical care units were randomized to either intensive glucose control (insulin infusion with target blood glucose between 80–108 mg/dl) or to conventional glucose control (insulin infusion begun if blood glucose was over 180 mg/dl, and discontinued if blood glucose dropped below 144 mg/dl). Severe hypoglycaemia (blood glucose below 40 mg/dl) occurred in approximately 6.8 percent of intensively treated patients compared to 0.5 percent of conventionally treated patients. The study showed no difference in length of time in the intensive care unit or in the hospital, or in other major outcomes such as time on ventilators or need for dialysis.

<http://www.newswise.com/articles/view/550381>

http://www.diabetes.org/for-media/pr-NICE_SUGAR-study.jsp

On the first day Don was in Intensive Care this research was pushed to us with the qualifier that taking part meant only miniscule amounts of blood would be taken, but as this would be getting tested more regularly than normal, this would give Don a better chance of survival.

But Don was given many bags of blood over the time in ICU because his haemoglobin levels were dropping. He had 10 bags of blood over the last two weeks alone, always in an amount of two bags per transfusion. It was never explained why he would need this much, and I would dearly like to know why. Around 10 May, near the end, I was present when a doctor and nurse actually force-squeezed two bags of blood into Don as if it were an emergency. One of them was squeezing the bag while the other attended to the connection, then they changed positions with the second bag. I have no idea why this was happening. The notes record the times these bags were given as being hours apart, but they weren't. I would say they were given within an hour of each other. God knows why the records are different from what I saw with my own eyes. I would also like to know why, if Don's haemoglobin levels were so very low, and knowing how sick he was, why some days they did full blood tests eight, ten, twelve times a day? There is no way his poor sick body would have been able to make up all that blood. What in bloody hell was being done to him?

My family's belief is that Don was kept alive long after there was any possibility of recovery for just one reason – medical research. That's why his suffering was an abuse of human rights.



My sister, who worked in a Brisbane hospital, couldn't believe the filthy, chaotic state of the Sydney hospital when we were there. I think only people like us who spent so much time there would really be able to attest to the unhygienic habits of some of the doctors and nurses. One evening, we were astounded to see nurses bring in a pizza and walk about the ward eating it. One of them even leant over Don's bed. This in an Intensive Care unit, where there are extremely ill people, many of them dying. It didn't seem to matter how many times the wardsmen and women cleaned the toilets, and they did it often, they seemed to be always a mess. The toilet in ICU was often left with unflushed toilet paper trailing out of the toilet, and wet used paper on the floor. We did our best not to use our fingers or hands to touch taps and door handles in there, a habit we shared with most other relatives and visitors. We would take the time when Don was being treated to go out of the public hospital and across to the valet-served, marble foyer of the private hospital, two minutes away, to use their toilets which were always spotless and sparkling. I don't think it was because the cleaners were not working hard, it was clear they were always working. There were simply not enough of them.

The hospital's air-conditioning vents were filthy too. Dags of dirt and fluff hung out of many of the outlets above people's heads and you'd find yourself watching them wave back and forth in the breeze. No way, this time, was I going to try and pull one down to clean it, because it seemed likely there was even more dirt behind the vents. I never saw anyone cleaning the air conditioning, not once in all the times Don had to go to hospital. I doubt that it happens much at all.

Towards the end, I don't remember what I was thinking apart from trying to soften things for the girls and rub cream into Don's feet and arms so he would know I was there and how much I loved him. As mentioned he had Candida

Albicans all through his digestive system by that point, and the skin in his mouth was flaking away and white. He would let me clean this all away and rub in the gel which soothed the rawness. When I patted his face with a warm paper towel he'd relax for a moment and lock onto my eyes and I could go into his world for a bit. I felt as if my heart was broken over and over and don't remember much of what I did the rest of the time, who I spoke to, how I interacted.

How many hours and days did I sit with my hand under his chin? I admit there were times I wished he would die so he had no more pain. No more indignity. No more cruelty. Then I'd feel guilty because I knew Don's terror of dying in those filthy haunted halls. I think he was afraid somehow this place might hold his spirit and he'd never find home. Don and I were never churchgoers, but with our strong Celtic leanings we were in tune with something wonderful. Don was a very spiritual man and he sensed things – nothing spoken about. I just knew. He had a terror of dying in this hospital, and it was very real. Considering the recent debacle with lack of security in the morgue there in 2009 and that a body was lost for four days and allowed to rot, only being found because of the smell of decomposition, Don was right to be terrified

Around this time, the notes mention a "*loculated right effusion*". At the time, we were not told how and when this happened, or what it meant. I know now though that it is what happens when a Pleurodesis operation fails and fluid is trapped between the talc because of the failed surgery. More omissions.

By now, almost every entry by nurses and physiotherapists note agitation. As mentioned, this agitation wasn't mild; it was constant, fast moving and shocking to watch. Don went between this state and total exhaustion and sleep when his body just gave in. Again the cause of this extreme agitation has never been explained, even though it went on for weeks with gaps of rest in between.

The nursing notes have Don becoming agitated and throwing his arms about trying to pull out his tubes. It was still only the first week when Don bit through the ventilator tube one afternoon and, as the air gushed out of his mouth, looked directly at Melissa and me and said to us, "Help me". It was one of the very last times we were to ever hear his voice, unimpeded by tubes. We looked at each other and then the alarms went off and Melissa and I were bundled out. Don wanted us to help him to die. That was his choice. I don't know why we didn't press this at the time but both of us were emotionally pushed about. We were outside in the corridor for some time and I can see my lovely daughter's distraught face before me as I write this. Melissa and I still have nightmares about this event.

I have always felt I could fix things for my family. Don and the girls called me, with affection and as a stir, "the woman who gets things done". This time, this most important of times, I felt just useless, and it haunts me. They could have sent him home to die then. We could have all gathered there, at home, and Don be allowed to die. But this only happened four dreadful weeks later, after so much more suffering.

This event was absolutely shattering for all of us, Don included. Poor Melissa was heartbroken that we had not been able to do anything to help him; he was quite lucid when he looked at us and said those words. But back in with the

ventilation tube. Even someone with healthy lungs would have been hard pressed to survive the damage done to Don, but as a long term quadriplegic, he was never going to survive. To continue treating him, extending his life artificially, was wrong. It was too cruel. The family has serious reservations and questions about the purpose and ethics of ICU doctors and until they are answered honestly we have a right to those questions.

Two days after this event, a nurse mentions in the notes that the NICE study was overridden at times because of Don's low blood sugar level. Two junior doctors from Cardiothoracic mention a discussion with the admitting specialist. So although we hadn't seen Don's admitting specialist for some days, he was apparently still in charge of Don's treatment.

On 27 April, the notes say: *'plan is to stop meds which could cause general fluid retention.'* Two of these meds were drugs Don had been taking for many years for pain relief, one of them opiate-based. It is impossible for me to tell from the drug charts when the medications were changed and if they were replaced with similar drugs, but it worries me greatly to think about the dreadful withdrawal symptoms Don would have suffered had these medications just been stopped. It would have been the same as a heroin addict going cold turkey. This could explain the "++" agitation. They were very careless with medication in Spinal, as I witnessed. How could I know what they did in ICU? I can't read their illegible notes.

Somewhere around this point, Don was put into an infection control area. This was a small unit with a small central nurse's station area and four so-called 'pod' rooms. I was pretty downcast when I saw the room where he was to be put – and to spend the rest of his life, as it turned out, except for the few hours after his release when he came home to die. Thankfully, though, we had no idea how long Don was to be in this room when we first came into it. The pod rooms were small and dingy with half-glass partitions between them. Don's was on the inside and so, as the man in the next room often had his curtains across the adjoining window, there was no sky, no natural light and the air was stuffy. The environment in this room cut him off from the outside he loved so much.

At home, one of Don's greatest pleasures was to find a peaceful spot in the paddock and lay back in the chair just watching the wide sky and listening to the birds for hours. In the pod room, only sometimes could we see a small patch of sky, and that was only when we asked if the curtain next door could be pulled back a little. The bright fluorescent light had no dimmer switch so Don was either flooded by bright light all the time, or he was in darkness. I used to sometimes pull his beanie down over his eyes for him to get some small relief. As his arms were always tied to the bed, he couldn't even shade his eyes with a sheet. As a quadriplegic, even when his poor thin arms were released he was unable to use them to effectively shade his eyes from the bright light straight above him.

It is things like this which I find heartbreaking. The little things that could have easily given a small amount of comfort during his suffering, but were denied. As the moments of kindness bought tears then, so do the cruelties heaped upon him bring tears now.

One nurse promised to put Don next to a window, but that never happened. Another man got that spot. One evening, before he was put in this room, Melissa

and I witnessed this man running down the corridor to the fire escape, only to be forcibly returned by two security guards. He may have been ill but it was a pretty healthy escape attempt. He spent the next weeks tied to the bed in the same manner as Don. I never imagined someone in ICU could get up and run, but I guess it depends on your motivation. This event still concerns us.

When I look at the notes for the next few days doctors say he was again ‘+++ agitated’ and a nurse remarks that he was trying to pull his tubes out. Of course he was. He wanted them out. They mention that he had unexplained hypoglycaemia (low blood sugar) and that there seemed to be no explanation. I hope the NICE study had nothing to do with this. Someone with medical skill may see something in the notes on medications, nutrition and so on which taken together with other issues may explain not only this but why he was ‘haemodynamically unstable at times’. Don was by this time ‘grossly oedematous’ – i.e. full of fluid. On overload. Why was this? No explanations given. I asked the doctors and nurses but there was never any reasons given by any of them. I don’t think ten bags of blood could have helped.

If it was fluid in his lungs at this stage, why were all these other serious things happening to him? There must have been reasons for all of this. Most of the time I had no idea of the treatment he received, unless I saw them giving him blood, or if I happened to ask a nurse what she was doing when she was adjusting the tubes or whatever. The fluid in his body, trunk, arms, legs and especially his scrotum was unbelievable at times. His arms were always extremely thin because of the quadriplegia, but at times they were so filled with fluid you could leave fingerprints in his arms when you touched them.

There was still over two weeks of this to go and each day Don was worse, his lungs were worse, and his suffering worse. It was around this time that Melissa and Chris decided to cancel their wedding. People had been booked to come over from Greece and other places. I know life is not fair, but for our little family it was dreadfully unfair after what we had already been through. Melissa, like Alison, loved her Dad totally so she was okay about the cancellation, but she and Chris had to be feeling terribly disappointed alongside the grief. Chris had the right instincts about the hospital. He couldn’t handle the place, rightly claiming that there was something seriously wrong about the whole building. We all felt that, but he had to get out, which I understood. I felt the same. I don’t know if it’s built over something like a big black hole, but to even see the place on TV makes me nauseous. It’ll be a cold day in hell before I go back there if I have anything to do about it.

By day 16 in ICU – 30 April – Don’s arms had been restrained for over two weeks and would be for another two and half weeks. He had been unable to talk to us after the first day or two because of the ventilator tube down his throat and the damage done by it, but he tried to communicate with his eyes and signals. The only communication device was a piece of paper with symbols like ‘make up’, ‘toilet’ and so on drawn on it. This was laughable in ICU in 2007. Don was unable to point in a straight and controlled way because of his quadriplegia anyway. He became extremely frustrated. Some input from the Spinal Unit’s occupational therapists could have helped him here, as they deal with high level

quadriplegics who need communication devices. But Spinal made it very clear Don was not one of their responsibilities. So we saw nothing as advanced as any communication devices made after 1940.

Again they extubated him – at 10am that day. Almost straightaway I could see he was in trouble as with the other times. I made sure they knew. It was not until 2.30pm that they responded. By this time he was breathing too fast, upset... very upset. Poor Don. Poor us, watching but unable to help. He was so special and precious to us. These continual failed extubations were ghastly and torturous for Don. He suffered so much, too much. All needlessly.

We have an ICU doctor's notes here: 'Dr L. required reintubation. *Progressive type II Resp failure.*' I am now reading notes made by a Dr W. on 30 April. Yet another doctor who probably had no real idea of Don's journey. This doctor spoke with me about the failed extubation, after which she noted: '*She understands his breathing is related to infection/fluid/alteration in lung mechanics.*' I understood what she said, but was not told what infection. Doctors and nurses knew by 30 April what those infections were, going by what Don's nurse told me five days later when I asked why there was so much bloodstained mucus being drawn off his lungs. But what would have caused 'alteration in lung mechanics'? Dr W. mentioned the possibility of a tracheotomy, and held out some hope with this procedure. I told her that Don had spoken to me about not wanting to be kept alive on a ventilator. It was explained that a tracheotomy would be a lot more comfortable for Don and that he may even be able to communicate once it was in (which, as it turned out, he couldn't). She said he may be able to do "weaning sprints", which might, just might, mean he would be able to breathe again. Of course I listened to this. It was the first positive thing I'd been told, but the decision was always to be Don's. I also understood the risks. She mentioned they were concerned about an infection he may have. That was the last I heard about that. I know this doctor may have meant well, but if she had understood quadriplegia and Don's respiratory limitations, she would have suggested letting him go then, as he wanted. His lungs were finished. ICU doctors must now have a good knowledge of Quadriplegia, because unlike in 1982 when Don was first injured and taken to the Spinal Unit, it appears people are now taken to ICU instead, as with the man in the next pod room to Don who was a new Quadriplegic.

How Much Worse Can it Get?

Infection control in this particular Sydney hospital is and has for many years, been dreadful. The first time Don picked up MRSA there was in 1982 – and that was when infection control was far better. In those days, staff and visitors alike were issued with a cloth gown which completely covered the arms and sides. Our daughters were then seven and four, and the nurses allowed each child her own gown. I had to fit it to them in such a way that the same side showed to the outside all the time. Melissa and Alison’s gowns had to be carefully arranged to meet the exacting standards of the day, so it would take some time on each entrance and exit, but was well worth it so that they could visit their dad. I remember one very senior spinal surgeon barging into the ward ungowned and unwashed, much to the consternation of patients, relatives and nurses. In 2009, Peter Garling pointed out this very problem in his report into NSW Public Hospitals where he says:

One of the worst aspects is that clinicians, especially doctors, are spreading infections from patient to patient largely because they do not practice hand hygiene before and after seeing each patient. A sizeable proportion of them trail infection around like sparks in a dry wheat field on the black soil plains at Mullaley, bringing great risk to the patients.

Each time Don went back there, we noticed standards getting laxer. Once in 1994 he was placed in a bed opposite a very ill quadriplegic man who had Aids and Hepatitis C and some other highly contagious disease. I would watch the wardsmen go from one patient to the other lifting and turning, and many is the time I saw them and some nurses and doctors pretend to wash their hands as I waited outside in the corridor.

In ICU’s so-called “isolation” ward in 2007, they used a throwaway plastic bib type of apron, which covers only about a third of the body and clothing. Apparently MRSA and other dangerous germs do not adhere to the arms, sides and back of the body. I also have no doubt that when we went down to the canteen the sides of our clothes, our arms, whatever, carried infection so that the next person to sit in that chair or at that table could take the infection to their relative or patient. For true infection control among such seriously ill people, staff and visitors need total cover. If they could do it in 1982, they can do it today. But the NSW Health Department’s response to my questioning of this practice was that it was “acceptable”.

In the tiny isolation room, when the nurses took off their useless throwaway aprons, they would throw them and they either landed in the bin or they didn’t. We saw many thrown in the general direction of the bin and miss, just to land on the floor where they stayed. The wardsmen and women, who did the cleaning of all the wards, infected or not, went from ward to ward picking up the throwaway aprons and putting them in the bin, then put on the same bits of plastic and went from bed to bed lifting and turning patients who did not have MRSA along with those who did, or those who had other infections. They leaned over patients

wearing these throwaway aprons, but the whole sides of their bodies and their arms were bare. It is not their fault, but they must have spread MRSA and other infections to many patients and wards in this way.

That was just one instance of the lax standards. There was also blood on the floor, dirty sinks, dirty toilets and dirty windows. You could not see out of the windows at that hospital, which just added to the bad feeling; the dreadful feeling. It felt dark, as well as dirty. I would put gloves on and try to sort out Don's room when I got there, and there were some nurses who kept the room in good order, but often it looked as if grenade had gone off.

The infection control in the Sydney hospital, especially that I saw in ICU, is a crime against the well-being of the patients; it was contracting infections so soon after entering ICU that made Don's suffering much worse. Melissa and I, who visited most often, came away from that place with rashes which would not heal for some months and sore throats which hung about. I had a large lump under my upper arm which took months to disappear. This lump, which appeared quickly and was disgusting, was full of pus and kept bursting and re-filling. Only about a month after Don died did it finally begin to shrink. It has disappeared for good now, but it took a few months before it stopped recurring. Both Melissa and I have not felt really well since being in that place, although we feel better as time passes.

One Sunday, Melissa and I were with Don and I started to have a panic attack. I was surprised to see Melissa was also really struggling herself. When they came in to turn Don, we walked outside and into the corridor, and Melissa said she felt a bit better already. So we went out into the open air for a short while and both totally recovered. I think it was the quality of the air in Don's room. I don't know what was going on in that little cubicle, but we were having real trouble breathing. When we went back the same thing happened. It only seemed to be in that small isolation area. It was often like this, but that day was the worst. It was as if in Don's closed-off portion of the hospital, the oxygen mix was not adequate. The nurses also commented on the stuffiness.

Amongst all this grime, Don was expected to fight the disastrous damage that the failed Pleurodesis had done to his lungs, but any chance he had of recovering was lessened by the unhygienic condition of the hospital. The doctors and nurses would say things like, "*They are building a new hospital soon, it'll all be better then.*" There are 300-year-old hospitals in Europe which are many more degrees cleaner than this hospital has ever been, and that was when it was not such a dying hospital. This problem will not be fixed with a change of hospital. There is a really odd attitude in there to hygiene, to accountability and to taking responsibility, and I feel very sorry for those good nurses and doctors who work there. It must be terrible to be surrounded by so much apathy and lack of hygiene, and even worse for seriously ill patients.

I was not told about Don's MRSA and Klebsiella Pneumonia infections when they first occurred. On Saturday 5 May, I noticed that when the physios and the nurses initiated a cough through Don's tube, they were bringing up a thick, pink, horrible-looking secretion. I asked the nurse what it was as I had never seen anything as horrible as this before. She looked at me in a sort of surprise and then asked, "Weren't you told that he has infections in his lungs now?" I had been aware

that MRSA was at the site of the arterial line in his groin – although that was only because I had asked why he was moved to a different bed. I was shocked by what this nurse said and asked her what the infections were. She then told me that Don had these two dreadful infections. This was a major disaster, on top of all the other major disasters. He had come into this hospital infection-free. With adequate hygiene and care this was not something that had to happen. With adequate hygiene and care, he need not have suffered this added attack on his lungs, made even worse by the load of fluid now in the right and left pleural linings. The NSW Government must take drastic action now to clean up our hospitals and keep them clean – at least as clean as Parliament House.

I assumed these two infections must have just been discovered, but when I asked how long this had been known, the nurse went to the notes and said the doctors found out on 30 April. In ICU in 2007 in Sydney, Australia, something as bad as this had happened during Don's care and not one doctor thought to inform me, his wife. I was there every single day of the six weeks from 12 April until the evening of 16 May when I left to get the house ready so Don could come home to die. I was there from about 8am every morning, yet not one person came and told me what was happening. Not one. They must be called to account for this unacceptable behaviour. It cannot be legal to act in this way. How could Don and I ever make decisions without being told or informed of the most important things to do with his treatment and now his dying? Yet again, as with just about everything else, I had to find out for myself.

That day I felt such anger and disgust at the whole hospital system, it almost overwhelmed me. Tubes into the lungs are never comfortable, but for the extended periods Don had them in would have been dreadful; and he would have been feeling extremely uncomfortable from all the fluid in his body, the cause of which was yet again never explained to me, although I asked often. Tubes hanging out of just about every place they could hang, and a body riddled with fungal infection. His mouth was flaking away and painful. His hair was unwashed apart from one time in his whole stay in ICU. I would mop it with a warm washer to try and get the smell out of it. His lungs were so full and draining constantly with fluid in the pleural linings, with the lungs themselves filling up with thick bloody mucus caused directly by the dirty hospital and bad infection control.

By the beginning of May, the first sepsis – toxins in the tissue or bloodstream – is mentioned in the notes. I know this is to do with infection, but am unsure whether sepsis is a whole body thing or if it was confined to the lungs. I was never told about this. It is noted that his feeds are not being absorbed as well and he is less responsive. There are many reasons for his feeds not being absorbed, but I know that if one has severe *Candida Albicans* throughout the digestive system, it is unlikely nutrition will ever be adequate. This is where the high potency probiotics we had obtained would have at least helped, but an ICU doctor wouldn't allow such "dangerous" treatment. Obviously her knowledge of nutrition and absorption problems was far greater than ours; I mean she was the doctor. Nothing was going to save Don's life, but his dying would have been much less painful had there been decent care given.

Nursing notes often mention Don's unequal pupils. We noticed this many times and once Melissa and I noticed that one pupil was elliptical for a time.

We drew a nurse's attention to this and it was quite pronounced and actually scary looking, almost alien, but she didn't note it down and when she came back again it had gone back to being one pupil bigger than the other but both round. We have no idea what this was all about.

Now there is 'line sepsis' noted, although I was not told about this at the time.

I feel sick to my core writing this. I have to stop and take stock and with renewed shock realise that all this was happening to one poor frail man, who should have been home and anticipating the wedding he had so much wanted to be a part of; something he could have done if they had only acted properly, and treated his lung conservatively.

I cannot get these dreadful images out of my head. I try to see Don as he was before he was filled with infection, sepsis, fluid and God knows what, but I cannot. I see my beloved husband tied and gagged by tubes, both lungs drowning and full of fluid, and with MRSA and Klebsiella Pneumoniae, so that even with the ventilator he was struggling to breathe. I see him with his tongue being forced painfully in and out, as he moved towards yet another respiratory arrest, aware he had no chance of survival. Never in Spinal, nor in Intensive Care, are the failures to act noted.

I am 56 years old and I have seen some terrible things. For three months Don and I watched his sister Judy die horribly from cervical cancer. I watched my own mother struggle with end stage cardiomyopathy and other problems. I was with Don in hospital for seven months when he broke his neck, and afterwards I saw and experienced the worst of human cruelty towards him at times, as well as a few remarkable instances of compassion. But his last five and a half weeks spent in this hospital were just horrible; all of which would have been avoided had they not done the original dangerous and unnecessary Pleurodesis. But once done, Don should have been treated with compassion in ICU. That hospital caused the damage, as supported by Dr Duflou's report to the NSW Coroner but when Don was overloaded on carbon dioxide and their hotchpotch of ever-changing medication and was hallucinating, many of the staff treated him as if he was an imbecile and with cruelty.

On the days when good nurses were on, Don would be so different, which made me wonder what had happened to him when we were not there. But he couldn't tell us, because of the ventilation tubes in his mouth, and eventually the tracheotomy. Sometimes when I arrived at his bedside, I could sense that something was terribly wrong and he tried to not allow some nurses to touch him when I was there. He would flinch away from contact from some nurses and not allow them to touch him if it was possible for me to take over. Others, the good ones, he would do his best to be co-operative with, when he was able. What he must have experienced, with his arms tied to the bed for five weeks and mouth gagged by tubes, is far worse than anything I have suffered or dreamt in my worst nightmares.

By early May, according to the hospital records, neither Spinal, ICU nor Respiratory seemed to want to have the care of my husband. I guess ICU was stuck with him. I knew what he wanted and that was to come home and die, as he knew was inevitable. But there were some issues with them trying to make one department or the other 'responsible'. Would that they had been responsible from the beginning. It's hard to feel anything but disgust for these people.

CHAPTER 16

Tracheotomy

Alison noted on 3 May, *'Tracheotomy put in and he is doing really well after the operation, things look good. Later in the afternoon he became really agitated, was agitated and awake all night.'*

The girls got really excited when Don had the tracheotomy, an operation which inserts a ventilator tube directly into the trachea or windpipe, through a hole cut in the throat, to enable breathing. They were so hopeful that this operation might be the turnaround for him. The answer, the miracle, which would allow their father to go home. But all the tracheotomy really did was to give Don some ease from the ventilator tubes in his mouth, which was a mess from weeks of tubes.

The main reason Don and I agreed was so the ventilator tubes could be removed from his mouth. My brain held a small sliver of hope, though my heart knew better. Don, I knew, was just doing whatever he could to get himself home to die. In the times Don was calm, we would often just sit together and I would tuck my hand in under his ear, on his neck. He would lean in on it for comfort. We comforted each other this way. Even at the worst of times, Don would look at me for a long time and I know he was concerned about me. He was unable to control a lot of the agitation and hallucinations, but I knew that in some part of him he was sort of sailing above it all until it was over. My brave and noble man knew there would soon be an end. He would just have been afraid, as was I, of what new device they would come up with that would inflict more suffering, if that was possible, before his body succumbed. He wanted to get home so badly.

Drs W., L.Y. noted, *'Day 20 admission post respiratory failure from Pleurodesis'*. This note admitted that the Pleurodesis had caused the respiratory failure, but no one ever told me. Over and over I find similar admissions in the medical notes. How can the Health Care Complaints Commission assert it was not the failed surgery which caused Don to have the first arrest? What would cause the HCCC's medical investigators to make such an obviously false statement, directly contradicting what ICU and cardiothoracic doctors have noted in the medical records? This strange behaviour alone needs investigation.

When Patsy, Don's first cousin, walked into the ward, Don's face, as earlier with Neil, almost split in half. I know he had us, but he needed his old family as well. She brought many a smile and tear to Don's face while she was there and he to hers. A woman in her mid-seventies, she had travelled all the way from Maroochydore in Queensland because of her family feeling. I think that her being there brought a happier few days for Don, if there was any happiness possible. They shared a wicked sense of humour and I felt myself smiling at the pair of them. She is definitely one of the goodies on this planet.

Our good friend Carmel came from home and stayed about five days. She thought it would be nice to sit with Don and quietly read to him, but this was not to be, beyond a few lines. It was a particularly bad time for Don. His meds had been all changed about, he was extremely agitated, and nothing further from a

quiet calm room in ICU could be imagined. It was chaotic. But she came, and she kept Don and me company, and she cared.

She has gone on caring since Don died and our friendship, if possible, has deepened. Don liked Carmel, but as normal, if he liked you, you got a bit of healthy stirring. Carmel didn't always know when he was serious or not. He was seldom serious with her. She was always a great visitor to us, often just arriving at our house and sorting out her own cup of tea and ours when things were busy and just staying an hour or two. It was a big deal for her to come down to Sydney as in the past decade Carmel had lost her whole family – mother, father, brother and sister. Sometimes, as with Patsy, those who have had some deadly life blows have a deeper understanding. I remember looking at Don one time when Carmel was in the ward, and he caught my eye and had the biggest, cheekiest smile at her expense. He was still there underneath all the garbage they had piled on top of him, fed into him and taken out of him.

Along with that cheekiness and the play, there was always a dignity in him. Melissa and Alison have it also. It transcends what one would expect in hard times. Beyond all the garbage, noise, filth and suffering, it was as if we were surrounded by waves and waves of love. You could feel it.

The only other visitors he had were a few hours from a nurse called Donna from home, and towards the end a visit from Chris's mother Rula and a cousin, Maria. Rula and Maria were visibly upset at the state of the place, but a wonderful thing happened between Don and Rula. He kept looking at her and patting her hand. Something about how she looked meant 'mother' to Don. She does resemble Don's maternal aunt and his own mother. She seemed to understand what was happening, and this visit made him so happy. He drew comfort from Rula being there. Lucky for them he was so good that morning because the afternoon was dreadful. He was shockingly agitated and hallucinating so much he couldn't physically see me. His eyes were darting everywhere as though he could see things we couldn't. He was absolutely terrified.

Sometimes as I write I wonder if I can go on with this. The sun shines outside, and there is a tinge of cool in the air. But I persevere because until I expose what happened to Don, I cannot walk in the sunshine, or be light hearted, or have any sort of life at all. The damage inside me is deep but I know and have faith that out of what I am going through, and out of what Don was put through, something really good will emerge, and that if the will is there, things may improve just a bit. I don't have a choice but to keep going, to see this through. To turn away now would be to condemn myself to only half a life, which I know would break my wonderful Don's heart. I know he would want me to live, to walk in the sunshine, to be happy again. But sometimes when the spirit is weakened by reliving these experiences, it is so hard. I have to remind myself how strong I am, how wonderful our family was and will be again. I know that by persevering, I can begin the healing, not only for myself but for our daughters. And so back to the darkness of that hospital's ICU.

Doctors note, '*ARDS/pleural effusion leading to respiratory failure.*' ARDS, or Acute Respiratory Distress Syndrome, was caused by the surgery he had. The notes mention what caused Don's condition too often for Cardiothoracic to

deny this. We discovered the condition of ARDS on the internet, which some of the doctors seemed to think was hugely funny, and “humoured” us. But we were spot on.

A nurse notes, *‘patient very agitated at times due to unable to communicate.’* You had to be there to see how hard Don worked at communication, but he was always exhausted after this effort and it was so hard to know the meaning of what he was trying to express.

By now Don’s left pleural lining was draining quite substantial amounts of red-coloured fluid daily. He had a left lung which would not stop producing fluid, a right lung which was beginning to re-accumulate fluid and both lungs full of bloody muck from infections, and now they said he had Klebsiella Sepsis. His body was dreadfully swollen below tummy level; he was swinging between extreme agitation and total exhaustion, on and on.

Then a physiotherapist reports: *“blood-stained plugs”* coming up from Don’s lungs. Blood-stained plugs! I feel sick as I think about him trying to breathe past all this. Physios treated Don with great kindness, and I honour their dedication and insight here. The bulk of the rest of the time was a tragic, disgraceful disaster with doctors and nurses trying to patch up things as they happened, like the little Dutch boy putting a finger in the dyke. There was no sign at all of any Spinal Team input, despite the fact spinal medicine is unique and each patient’s needs are different. The other doctors recognised this. Don should never have come into the hospital under a Cardiothoracic doctor, but under Spinal.

The doctors’ plan after the tracheotomy was to try and retrain Don’s lungs to kick in by ‘sprinting’ him. This meant that every hour between 8am and 8pm, I believe, the ventilator attached to his trachea was to be removed, and Don was to be left to attempt to breathe by himself for five minutes or until he needed a rest. The first day I watched him do this it was done properly by the nurse and at the regular intervals instructed. She was an excellent nurse, and she tried hard, but he was so weak and drowning in infections as well as pleural fluid. An ordinary healthy person would have little chance of being weaned off the ventilator at this time. Don had been on that ventilator for over 22 days and was full of infection and having odd blood readings that made no sense. What was wrong with them all that they couldn’t understand – or acknowledge, at least – the hopelessness of his condition?

Under the circumstances this sounds extremely trivial, but Don had entered hospital with a very long big toenail. I never cut his toenails at home because his circulation was poor, instead leaving it to a trained podiatrist. But the podiatrist who was due to visit just before we left home never showed up and we had more pressing concerns at that time. In hospital, one of the nurses arranged for a podiatrist to come and trim this nail as it was getting caught on the sheets and in danger of being accidentally ripped. I was dismayed when I watched the hospital podiatrist dig into Don’s skin when he was cutting the nail. He seemed to have no comprehension of the dangers of breaking Don’s skin in such an infected room. We had just wanted the nail trimmed and knowing the amount of infection in that ward especially, another wound was the last thing needed. I watched that toe like a hawk for any signs of infection – which was silly when

I knew what the infections were already doing to Don. I just didn't want any more insults inflicted upon his poor body.

Some days, and increasingly, it was awful to listen to the noises from his lungs – it was like crackling paper. When I was there and Don's hands were free, he would communicate with his hands and eyes. He would tap his chest to indicate he needed a physiotherapist to help remove some of the mucus from his lungs and one would always come straightaway if possible. They were always willing to help, and I cannot praise them highly enough.

It was visible to everyone by this time that Don was dying and all the treatments were simply extending his suffering, but on went the charade. A doctor noted: *'Type II respiratory failure post VATS Pleurodesis'*. I wonder had the admitting specialist and staff read these notes, if they remembered how glibly the admitting specialist responded just after Don's first respiratory arrest, when he hastily asserted the Pleurodesis was not responsible when all the other doctors, even respiratory, state over and over what caused the arrest and ARDS?

The nursing notes at 4.15 am on 8 May make no sense to me. The nurse writes: *'Initially very agitated, trying to pull out tracheotomy and NG [nasogastric] tube by hooking fingers in lines, spitting on nursing staff... breakthrough Lorazepam given... and then later sleeping for long periods.'* In all the 35 years I have known Don not once ever, even in the early days when he had the odd beer or when very angry over something, did he never spit at anyone. Never. For Don to spit on anyone, man, woman or child, would be unthinkable. I do know that when he tried to speak past the tube, he would use his tongue and make a hard "T...T...T" sound. But if he did spit on them, I wish I knew the other side of what was happening. If he consciously spat at anybody, something really awful must have occurred to make Don do this. They only recorded what he did, not what they did, so I will never know. But I know enough not to take these notes at face value. They could do what they liked to him and us, but were we to do anything it was duly noted with meticulous precision. So now I am noting down some of their failures and abuses, for the record. I'll never know what was done to him when I was not there. Maybe that's a good thing. It's hard enough already.

The 8th of May had to be one of the worst days for Don especially and also for Melissa and me. Our friends Neil and Renate visited on this day and witnessed the dreadful nursing 'care' he received. Arriving at the hospital about 8.30am, I assumed that Don would already have begun the 'sprinting' breathing as ordered by the doctor. This should have begun at 8am. At 9am, when it was due again, I asked his nurse when she was going to begin the sprinting exercises. She looked at me as if I was stupid. She appeared not to know anything at all about this. It would have been in the notes, surely, because they started it the day before. I asked her to check. She finally began at about 10.30am and was in an obvious hurry for Don to complete this training as she stopped as soon as she decided it was time, whereas the previous nurse had taken careful note of what Don was experiencing. Considering he was not long away from dying, this failure of a nurse to follow doctor's orders is a moot point, but shows the lack of continuity of care. I seldom saw anyone I knew to be a senior nurse to complain to, a problem made worse by the complete lack of identification of all staff.

This nurse's notes reflect nothing of the day we experienced. When I came into the room it was disorganised and untidy. The bins were overflowing; lids were off mouth and face creams and the toothpaste tube. Sheets, cables, tubes and other things were in disarray. There were used towels, gloves, tubes and other material lying around. This nurse seemed unable to get any order during her whole shift of some 12 hours. She spoke to Don in what I can only describe as a nasty fashion, which he was very aware of. Over-explaining, over-loud, right into his face, ad nauseum, as to why she couldn't do certain things, as if he was retarded or brain damaged. She seemed much more comfortable outside his room doing notes or something. I spent much of the morning cleaning Don and his room and reassuring him I was well aware of what the nurse was doing, or not doing.

How on earth could anyone be actively cruel to any human being who was dying? I just don't understand this and hope I never will.

When Melissa arrived at lunchtime she remarked within minutes of meeting this nurse that it wasn't going to be a good day for her dad. It was that obvious. On this day Melissa offered to stay with Don for a couple of hours while I went to the shops to buy a couple of warm tops, as I had not thought we would be down in Sydney this long and I had no winter clothes. Melissa said that as soon as I went, that nurse showed her true colours and didn't even bother trying to hide her attitude. Melissa said: *"She ignored requests for things Dad needed as if she didn't hear me, which she must have done. I stood right in front of her."* This nurse reverted to her former obsequious passive aggressiveness when I returned.

In ICU, people are critically ill. Most are facing death or its prospect. Most are in a lot of pain, and emotionally it is a dreadful time for the patient and those who love them. Nurses like this cause so much 'hidden' pain, almost like they are punishing the patient for making them work. That's how it felt.

When I returned about two hours later, Melissa was quite upset and Don extremely agitated. But the physio reports that same day that Don was alert and cooperative. It was only when this nurse came near him he began to thrash about. I have to wonder about this. I had noticed this day that when I went to soothe Don's sore mouth with a swab and gel he bit down hard for a time on the swab, as if his tooth was aching and he was biting to ease that feeling. He did not seem to be totally aware of how hard he was biting and I warned him to be careful or he might end up hurting himself. He was in two minds this day, at times really lucid and at others it was as if he was in another place, and seeing other things. He would not let this nurse clean his mouth or do anything to him he could avoid.

The doctor and nurse couldn't get Don's blood pressure down and kept giving him a drug that didn't work. I asked the nurse to use the Adalat capsule as it always worked at home. She wouldn't. I told her the ICU pharmacist had approved it. Don's blood pressure was becoming alarmingly high for a quadriplegic. She finally agreed. I warned her not to give it to Don by putting her fingers inside his mouth. I offered to do it but she refused. I told her he was biting hard on anything which went into his mouth and to be careful. Neil and his wife Renate were there at that time.

So she went ahead and put her fingers in his mouth to deliver the Adalat, which has to be squeezed out of its capsule under the tongue for speed. He bit down hard and hung on. It wasn't intentional. His eyes weren't with it. We pried his mouth open and she ran out of the room calling, "He bit me, he bit me", demanding blood testing and showing everyone, then came back to demand that we say we saw what happened. She was worried about Aids or something but he'd had so many blood tests, it was more likely he'd get something from her; after all, he'd been technically celibate since his accident in 1982.

His blood pressure came down straight away, as I knew it would. Poor Don then put his own fingers into his mouth (he could not feel his fingers due to quadriplegia) and bit two of them and lacerated his own mouth. I think he was in dreadful oral pain that day due to the remnants of the tooth that had been knocked out on the night of his first respiratory arrest. It was rotten and sharp and obviously causing him pain.

There was no more 'sprinting' as the doctors made the decision later that day he was not tolerating the training. The failure of this was the end of the bag of tricks, thankfully. I didn't leave that evening until a new nurse came on shift and I was assured things would be better.

All this time, Don was almost totally unable to communicate any wishes apart from yes and no and rolling his eyes in disgust. Sometimes we would just look into each other's eyes for ages and we both knew how bad things were and how stupid it all was. By this time, it felt to both of us like Don was being used as a medical research guinea pig. On one occasion, a nurse left Don's feed off but the insulin on. If not rectified, this would have left him hyperglycaemic, possibly leading to a coma. The nurse was told to turn the feeds on by another nurse, who appeared to be more senior, and who was visibly annoyed. Strange things like this happened off and on, but were never noted.

The days wore on with Don becoming more and more septic. I pointed out to nursing staff that Don's fingers needed cleaning and bandaging where he had bitten them, as this had not been done. It was done eventually, but again I noticed as the days passed that the bandage on one seemed not to have been changed. I mentioned this and was told it had been changed. It had a green appearance. Turns out it too had grown MRSA. Don was riddled with MRSA at this stage.

Before I go onto Don's last days, some incidents need relating.

There was a young woman in a room opposite Don's. She was about 32 and had brain damage from an accident. Though she had serious mental problems, she too could be lucid at times. One day, the four nurses on duty were all at the desk station, and one of them mimicked the way the woman was speaking and they all laughed. The young woman called out, "*I hear you out there laughing at me.*" The main nurse replied, "*We're laughing at something else out here, not you.*" They were laughing at this young woman who had the misfortune to be in their care. I should have remembered to say something to her relatives. I wish I had. I know there are many good nurses but when one acts like this towards a sick person, the other nurses should speak up. It's the only way to ferret out such unacceptable behaviour.

When one new patient was brought in, his room was sealed with a thick, solid plastic lining across the door – which ICU subsequently denied ever happened. I saw no one enter the room except one nurse who wore complete covering and a mask and rarely left the room during an entire shift. The patient must have had a serious infection that was worse than MRSA. Staff seemed very afraid it would spread, but I saw some breaches of hygiene that could have allowed whatever was in there to get out – like the special nurse having physical contact with nurses caring for other ICU patients. Hands were touched as equipment was exchanged. Cross-infection would have happened.

A team member of the admitting specialist now notes: '*Ongoing ventilator dependence; grossly oedematous; hypo-albuminemia*'. We were never told about this last development either of course, but my sister informs me that hypoalbuminemia is connected to malnutrition. I know they had Don on standard naso-gastric feed, although there are higher grades of this feed with more protein content. It could be the cheaper feed version was responsible for the hypoalbuminemia. How could this happen if they were in total control of his feeds and the quality of them? Five weeks of the lowest standard feeds, with the lowest protein levels in them. The nutrition levels were important for a dying man because the hypoalbuminemia further added to his suffering.

There was one day when Don received four units of blood; at 5.30am; 8am; 4.30pm and 7pm. This need for blood has never been explained – why so much? I was there, as mentioned, when they squeezed it as if it had to be delivered immediately. I never was told nor understood what was going on. I did ask – but the answers were vague.

Around this time I recall meeting one young doctor who was compassionate to Don's suffering. It was he who took the time to write a letter for Melissa and Chris, after they cancelled their wedding, to show to all those they had left deposits with in locally. This good doctor took the time to explain the situation, in the hope various people involved such as the motel, the florist and the car hire company would deal more kindly with Melissa and Chris financially. It was this doctor who on more than one occasion touched Don on his shoulder with kindness, something too many did not do. Just a touch of fellow feeling reduced us to tears.

Months before going to hospital, Don spoke to me about something like this happening in the dental surgery. He had been in dreadful pain due to many bad teeth, caused by a constantly dry mouth due to medication. As he was undergoing yet another extraction, the dental nurse just touched his shoulder and squeezed it once or twice. When Don told me this later at home, it brought tears to his eyes. Compassion takes only seconds or less to deliver, but can give so much comfort to those who suffer. I hope this doctor can recognise himself if he reads this, and realise that we did notice and do remember.

I was not told by nurses or doctors that Don had now developed a broken pressure area under his scrotum. As mentioned already, a nurse came to me days later and told me "on the quiet" in the waiting room, as if it was a secret. Why did that nurse have the feeling it had to be whispered information? Don and I should have been told openly at his bedside, as should happen all the time. I nursed him on my own at home, with few days away and no shift breaks. One time in the 25

years since his accident he was confined to bed for six months, continuously, but he never developed one broken skin pressure area mark on his body, because I turned him regularly and noted any problems and made sure he was dry. In ICU we were always hustled out for the turns. To this day I don't know why I allowed myself to be pushed outside and didn't stay to watch. I do remember feeling in a weird sort of mind state where I didn't seem to have much will, like I was on auto pilot and going through the motions. Inside my head was a mess.

On the morning of 12 May, Don was extremely agitated. He had a lot of pain and was almost pulling himself out of bed by his restrained arms when I arrived at about 8am. The nurse commented on the uneven response of his pupils, as was now visible and commonplace. This unevenness came and went. It appeared that something neurological was going on. I have since discovered in the medical literature that neurological symptoms were one of the adverse outcomes of the NICE sugar study.

Something odd happened to Don on this day. After a morning of extreme agitation, by noon he began to be very sleepy. At first I was pleased for him because he seemed to be having some relief and rest and I prayed for him to have any respite at all from the dreadful suffering. Three or four hours later he was very hard to rouse. I went for something to eat. Then I had a strong feeling I should go back and almost ran.

Nurses and doctors were crowded around. No one could wake him. Nobody had thought to phone me. It was fortunate I'd had the instinct to return. The doctor took me aside and said Don may have had a brain bleed and to be prepared. I stood by my lovely man while they got him ready for the CT scan, thinking that this was the last time I would see him alive. I called the girls and sat with Melissa and my sister Jackie in the waiting room. An hour and a half later they brought him back on a trolley and he was sitting up a little and had his beanie on. He was wide awake and smiling fit to burst, trying to laugh as if he had been somewhere wonderful and had some sort of joke to tell us.

The doctor was stumped and shook his head as to how and why Don woke up so brightly after being unconscious. It was truly amazing. He smiled for hours, beautiful smiles. He tried and tried to tell us something. Of course we tried to understand, but he couldn't speak past the tubes. We just realised something wonderful seemed to have happened. He was animated almost to a state of extreme excitement. I wish he could have conveyed what it was he experienced. Something very special had happened.

The odd thing is that days later, in the very next room to Don, another patient had the same event. He also couldn't be woken; everyone was panicky and he was taken off to have a CT scan only to return wide awake and alert. I have to query, could there have been something contagious or to do with medications which happened to both of them? The doctor's notes about this incident are illegible.

Not long now Don, only a few more horrible days and then it will be all over; for you over three years ago and for me as I sit here remembering, it will all be over one day, I hope.

The next day, Don was back to the suffering and was very agitated. I looked at him for so long sometimes and wondered how were we going to get out of this dreadful place? The wards and the little room were dirty, with the only colour being the poster-size photographs of scenes from home I had stuck onto the grubby walls. I would see Don looking at the photo of our kelpie Thorn, then at the trees over near the dam, and I was with him sometimes for the moment, almost out of body. There was one set of photos I had stuck onto a sheet. The top photo was of his two beautiful sisters, Jeanette and Judy, who were both dead. The bottom picture was of our two daughters, just as beautiful. Don would get me to bring it over close and he'd look at his sisters for ever so long, trying to touch their faces with his poor screwed up hand, then look down at Melissa and Alison and do the same. I know he drew something from those photos more than any other in the room. His family was one which suffered much tragedy, and sometimes his eyes looked so sad, the memory breaks my heart. He was such a wonderful dad and husband. Always our welfare came first and he would often bring home little treats, or buy Melissa and Alison a pair of earrings or something, just for the pleasure of giving. To see him like that, in among the grime and the chaos, is still like a series of images in my head, as if it is still happening. I know it isn't and thankfully he no longer suffers, but not one bit of his suffering would have happened had the doctor who did the Pleurodesis been more careful. He was on that month's holiday we were told about and nowhere to be seen in our grotty little corner of the hospital complex.

It was on this day that we again requested Don have his hair washed. As mentioned, this only happened once in five weeks in ICU. They had the equipment and we offered to help, but he was not to get this wish. Don was always very clean and having his head feel like this was upsetting him. We mopped it as well as we could but it must have been driving him crazy. There was often the time to do this small thing, as I was there every day and did as much of Don's personal care as I could. Oh well, not important now, but it was very important to him at the time. I remember going out to see how Don's nurse was coming along about getting the hair wash set up, but there she was at the desk with another nurse, looking at a winter coat selection on the net!

And So Home to Die

The last four days until 17 May were bizarre. On reflection, Melissa and Alison, my sisters Veronica and Jackie and I all felt as if we were a part of an orchestrated event. We are still puzzled by the surrealness of this time.

By 14 May, Don was drowning in infection. He was grossly oedematous, had a nasty pressure area, had sepsis in his body from all the infection and had developed hypo-albuminemia. He couldn't be weaned from the ventilator because of the damage from the failed Pleurodesis. Finally, ICU and Cardiothoracic doctors admitted he was dying – something Don and I had accepted since those first days in ICU.

In all the time Don had been in that hospital and despite all that was going on, up until this time I had come across a social worker only once. I can find no notation about that meeting. When I told the local social worker this she was shocked, as she had assumed things would be different with such a serious illness. Now we were about to be drowned, almost assaulted, in a sea of 'concern'.

That day an ICU doctor, the ICU Social Worker and Don's nurse met with me to say that Don was dying and treatment was just prolonging this. I had known this anyway but thought to try and get something for Don out of this by asking that all effort be made to get him home to die. I explained to the doctor that any decision about Don was to be made by Don, and Don alone, and that she should talk with him. This doctor's notes record that when she explained this reality to him, *'he looked at me as if to say, "It took you that long to notice?" and he expressed excitement at being able to go home to die.'* Finally, after five long, painful and brutal weeks, someone actually looked at him. Looked at him and understood. Now he was officially dying he became important, his wishes became important.

So now, after all these weeks of suffering, all Don's treatments apart from pain relief, antibiotics and fluids were stopped and Don became almost immediately lucid and calm. How do they explain this to me?

The hospital undertook to organise a home ventilator, which we agreed would be taken away at some point after Don arrived home. They said they would try to organise a ventilator from our local area, for home, so that Don could have some time there and when he was ready he would choose when to have it turned off. He was told it was likely he would die a couple of hours after turning the ventilator off. We were going home, that was all we could think of. But I could still touch his warm skin, selfish me. I began an internal countdown as to when my husband was to be dead and gone.

From this time until the day I left for home, late on 16 May, there were too many people talking at us. I recall one staff member go right up to Don's face and say loudly, *"You know you're dying, don't you?"* And then seconds later another medical staff member was right up at his face. He wasn't deaf. It was like being thrown into a vortex of different people. We were supposed to know who they were and why and what they were doing; it became crazy and very disturbing. Don, the girls and I had such little time to be with each other and time was so precious.

Like most of the time at the hospital, 16 May was chaotic. My skin felt numb and tingly and when I spoke, it was as if it was coming from somewhere outside of me. Much of the time I was on autopilot. People seemed to be crying all round me, except Don, the girls and me. All seemed to be confusion. My daughters have told me they felt the same way.

Members of the hospital staff kept saying how lucky we were to be going home. We were exhausted. I kept hearing about how good they were to get us home, how lucky we were. How lucky we were? After what had been done to him and us? I don't think anyone could call it lucky. We were told many times they had never heard of an air ambulance taking someone home to die. Their spin was that we were "lucky" to be able to go home. Our spin was that anyone who gets out of that hospital alive is lucky, even if they are only going home to die.

Don became serene and peaceful. He would look at each of us for a long time as if he was making a memory of us. He constantly indicated his concern for our welfare. The day before they were to tell us the schedule for getting Don home however, the nurse on duty when I arrived that morning was absolutely dreadful to Don. Everything was a bother. I asked her was she aware of what was happening and she seemed unconcerned. Finally when I had had enough of her bad attitude, I finally found the Nurse Unit Manager (NUM) and explained what was going on and asked that nurse be replaced in the circumstances. The NUM told me, "Sorry, the nurse hadn't been informed". One would have thought at changeover Don's nurse might have read the previous notes. But even so, had it just been another 'normal' horror-filled day for Don, she should have had empathy and been pleasant.

After noon, she just seemed to disappear, thank goodness.

Then, at 4pm, two days before Don was to die, the speech pathologist finally arrived. Unbelievable. After five weeks of Don in there unable to communicate, weeks after the tracheotomy, two days before he was to die, they send a speech pathologist. She became quite short with Don because she felt he wasn't trying hard enough, that was clear to see. She didn't seem to make the connection with the obvious and very visible fact that he was close to death, weak, exhausted and just holding on. Her absurd notes say: *'Poor mouthing and limited understanding of over artic and intra oral pressure strategies. Poor learning and comprehension not assessed for phonation valve due to nausea. Rec (1) Encourage more use of mouth [something] and resp effort for communication (2) Use T/N Q's where possible plan R/V for phonation value trial.'*

Another bizarre incident happened with a foreign nurse at this time. My sister Veronica, as a 25-year specialist renal nurse, noticed that Don's saline drip, which was delivering fluid, had been stopped, yet Don was still on a large amount of Lasix, a drug that removes fluid from the body. Veronica said if this continued the outcome would be like torture; he would quickly become extremely dehydrated and go into renal failure. So we asked the nurse to put the saline drip back on immediately. She refused. We asked her to ask a doctor to do it. She refused. It was noticeable that many foreign born nurses from certain countries seemed unwilling to bother the doctors at all. A dangerous attitude anywhere in hospital but especially in ICU. I went doctor-hunting throughout ICU and found a doctor who, within an hour, told her to put the saline drip back on. Only a day away from Don leaving, I was about to drive home. If Veronica had not been there and aware of the problem, Don would

have died in alone in the Sydney hospital and I would have been home, six hours away, waiting. He never would have come home – even to die. As with numerous other examples of bad practice, the nurse made no note of this incident.

You really have to wonder why trained people working in an Intensive Care unit do such stupid things, and you have to hope they actually were mistakes so you don't get paranoid about the frequency and stupidity of their errors. We did not need this stress at this time. Don did not need to be made suffer more, simply because the nurse seemed unwilling to approach the doctor.

In the early afternoon of Don's last full day the social worker announced that arrangements for him to be flown home the next morning were in progress. She said I would have to be there to meet the air ambulance, which meant driving home that night with the air mattress which was currently under Don. It was an organisational nightmare trying to get all the gear together and figure out a way home. My first thought was to fly, but the air mattress made that impossible. Don had to have that air mattress, even though he was dying, because the gentleness of that mattress underneath him and the comfort it gave him was most important. I needed to be gone as soon as possible, as I was told they would not release Don until they heard I was at the house waiting to receive him. But oh, how I would have loved to have had those last hours with him. To have sat beside him on the plane home, how much I wanted that. He was my life. It seemed so cruel that with all the people now gathered around, it had to be me at the house. Still doesn't make sense to me.

We needed to get going by about 6pm so as to arrive home by midnight. I had driven our VW van down to Sydney, but on this most important day it had been taken away for the day somewhere else in Sydney, we had no idea when it would be returned and were unable to contact those who had the van and we didn't have the luxury of waiting for it to show up. A crazy, bizarre situation knowing what was happening inside the hospital that day and how close Don was to death. My head was jumping all over trying to tie up all the many loose ends. After all these weeks, everything happened in a matter of hours. Melissa and Alison were like pools of calm amongst the madness and they need to know how much this meant to me.

All of a sudden, there was too much to do and organise, at a time when I really needed to just sit quietly with Don. Suddenly, after all these dreadful weeks, I was told I had maybe about four hours with my lovely man, and that the next time I would see him, if he did not die on the journey home, would be when he arrived home to die a few hours later. Before this, I had tried to spend as much peaceful time as I could with my husband, but his room seemed to become full of people, on and off all afternoon. It was crazy chaos. Sort of like a circus and people all seemed excited, like – I don't know, it was too bizarre for description. Even now I don't have the words for what I felt. But finally, Veronica, Melissa and I left Sydney at about 7pm, by rented car, because my van only turned up shortly before we were to leave. Thankfully Chris, Melissa's partner, realising the dreadful situation we found ourselves in arranged for a car big enough to take all the stuff we needed.

Before leaving, they told me that when Don arrived home, his GP and the palliative care nurse would be there, but wouldn't stay long. Therefore I would

be expected to manage the syringe driver – a syringe attached to a tube that goes directly into a terminally ill patient. Generally, in the weeks before death, patients learn to deliver their own morphine and any other medications needed when the pain gets too bad. It acts quickly. When death is near, it allows the patient or their loved ones to steadily increase the dosage as symptoms of distress arise. This makes the dying person comfortable. In Don's case it was also to combat the distressing and painful symptoms of the Respiratory Arrest he would suffer shortly after the ventilator was removed. Oh God even to lay these words out like this causes such distress because others read the words. I see the person I love with all my heart going through all this over again.

Near the end, helped and made comfortable thankfully by the medication, the person dies. This is not Euthanasia, as death comes by withdrawing an artificial aid, which is totally different. The medication just gives comfort to the person dying.

To ask a lay person to manage a syringe driver for only a few hours in between a patient's arrival home and his death, however, was shocking. Too much, and I would have killed him before we got to say goodbye. Too little, and he would have become distressed and suffered shockingly from the Respiratory Arrest which would have followed. The syringe driver had only just been attached when I had to leave Sydney. So I asked the hospital to arrange a private nurse to stay with us in the background and manage it. After all this time, and all that had been done to Don, it was expected that I end his life. Too much. Palliative Care locally arranged that nurse. It was so simply done, but would not have happened had I not asked. It meant I didn't have to botch my husband's death, as well as everything else going on.

We were then told that supposedly, the Sydney hospital could not locate a single home ventilator in all of NSW public health system. Due to this, they said the ventilator with which Don would travel home had to go back immediately with the air ambulance, so would have to be taken away as soon as he was in bed; in other words, Don would have to die before he was ready because the hospital wanted the ventilator back and wouldn't let us use theirs for a few hours. Don and I had to agree to this or he couldn't leave. We did agree, but only under duress. By this stage we would have agreed to anything so he could go home. I don't believe they had the right to ask for such an agreement.

When I queried this with the HCCC later, they said that ventilator belonged to the air ambulance, which was false. When I checked, the air ambulance confirmed it wasn't theirs. My sister Jackie stayed with Don at the hospital the next day and travelled with him on the plane and she said he'd been on that ventilator for some hours before the ambulance even arrived. If that ventilator belonged to anyone other than the air ambulance, then it could and should have been up to Don when it was removed. Why would the HCCC make such a false statement?

Don and I had been led to hope he would arrive home in the daylight; that he would get to see our beautiful place one last time, surrounded by trees and a haven for the flocks of native birds he loved so much. It's under a wide open sky a little way out of town and has a beautiful feeling of peace. Jackie flew home with Don, though initially they said she couldn't. So Don did have someone he loved and knew beside him on the trip. Alison had stayed next to him as long as she could

the evening before, and then flew up home early the next morning. She told me some lovely things that happened between her and her Dad that night. Ali put her head down on Don's favourite pillow for a rest. It was late and had been a hell of a day for all of us. She wasn't very well at the time and I was amazed how well she held up. He shut his eyes and indicated to her they'd both have a little rest. She said a few times she would open one eye to see if he was really asleep and he'd be doing the same thing. He was so much himself once he knew he was coming home.

It was the hardest thing I ever did to walk away from the hospital, knowing Don might not make it home. And when I did finally leave, I swore I would never return. Never. As we packed the hired car, it was the strangest feeling. Everyone was acting normal, talking about this and that, exchanging pleasantries, as if we were going away somewhere lovely on a sort of jaunt. Necessary though I know, because Melissa was driving and it was a dark foggy night and she needed her wits about her.

We arrived home just after midnight and phoned the hospital so Don's mind could be put at rest. He had been worried about us driving, knowing how shattered and exhausted we all were. We got the house set up for his arrival the next morning, and we were all there, his daughters, my sisters and one or two friends

Jackie spent the last day with Don until he arrived home and this is her statement, in her words:

17th May 2007 – At 8am I arrive at the hospital and go to Don's ward. I am staying with Don until the air ambulance can take him back home... It is the family's understanding, that there is no room in the aeroplane for Don to be accompanied by family. Therese, Melissa, Alison and the rest of family are already home. It is estimated that the transfer will be close to 9am. Don seems calm and is glad to see me. He is very alert. About 9am Nurse Rebecca tells us it will probably be about midday for the transfer. Don seems disappointed in the delay. Don can't talk because of the respirator. I ramble on about different things. Rebecca periodically removes the tube so Don can communicate. He is concerned about Therese and how she is going to cope alone. He wants the family to stay with Therese. The message Don was conveying was that he wanted to make sure that his family would look after his wife after he died. He didn't want her to be left alone. He was very sad about this. Also he felt that his late mother was with him and this comforted him. He was tired but calm. He was very alert. He wants to be hugged. Don was very anxious to try and communicate to me. Because of the procedures which have been noted he was unable to speak. Rebecca went to quite a lot of effort to help Don be understood. She removed the ventilator tube for a short time which allowed Don to mouth his words which were still very hard to understand. The social worker also tried to help Don convey his message using symbols on a sheet, but really to no avail. Don seemed very frustrated with her. Rebecca returned many times to help me understand Don. She was very conscious of making sure Don was as comfortable as was possible. Don was very responsive to her.

Don's room was that day for the first time completely sealed off, although he was already in isolation. The curtains were right round the internal windows and across the door. This was very odd and claustrophobic. We were not told why this happened. A staff member furtively looks into Don's area and sprays some kind

of substance on the floor in an arc. Don is aware of this unexplained action. She didn't say anything.

Later in the morning a doctor arrives with the portable respirator that will accompany Don home. Rebecca and the doctor fiddle around with the respirator for about an hour. Don is not happy with it. The tubes are uncomfortable. I'm never quite sure if he is comfortable with it. About midday Rebecca speaks with air ambulance and they tell her there is room in the aeroplane for an extra person to go with Don.

Rebecca speaks with Therese on the phone and it is agreed I will go with Don. There are further delays and so the air ambulance people won't be here till mid-afternoon. Don is not happy with the delays. He looks very tired but is very alert. He wants to get out of the hospital. I go out about 12.30ish to let my husband and children know what is happening. My husband will drive Therese and Don's van back home. Don seems concerned when I go but I assure him I am coming back soon.

About 3pm the air ambulance nurse and two ambulance officers arrive. Following hospital ward protocol they put the plastic aprons on and transfer Don onto a mobile bed. Don remains totally alert the whole time. As they leave the ward they dispose of the aprons. The air ambulance nurse is very no nonsense but is very good to Don, communicating to him what they are doing. We leave the hospital. The doctor who helped put Don on the portable respirator accompanies us out and hugs Don. For some unexplained reason she tells me it is her day off and she got called in. I hope Don doesn't hear this trivia.

Driven by road ambulance to the airport, Don's head is moving around quite a lot. I am able to get into a position to support it. Don is incredibly calm but still totally alert. He must be very tired. Arrive at the airport. Meet the air ambulance pilot. Don is transferred to the aeroplane. The air ambulance nurse, the pilot, Don and myself are the only people on the aeroplane. The nurse sits beside Don. My seat is at the back of the small plane. I can clearly see Don and he can see me. The nurse points out the Harbour Bridge. Don doesn't look. He looks relieved. He keeps looking at my face. I have to look away. I can feel tears burning at my eyes. I look out the window for a while until I can compose myself. The nurse chats away to Don. She points out the beautiful view. It is getting late. I look back at Don after wiping away my tears. He's looking straight at me and is smiling.

We arrive at the local airport. The road ambulance isn't there. The nurse is annoyed. The sun is starting to go down. The ambulance arrives. I give them directions how to get to Don and Therese's home. We arrive as the sun is setting. Therese and rest of family come out to the ambulance. It is a surreal experience. I blend back into the family. The rest of this part could best be explained by Therese, Melissa and Alison. It feels really crowded. Later my husband arrives with Therese and Don's van. Don wants his wheelchair. This is unloaded. I leave with my husband and young children. Don had made the trip."

Death Comes

Those of us closely involved, especially Don and Melissa, Alison and I, were very traumatised by the events leading up to this and then the hurried trip home to beat the ambulance, arriving at midnight the night before. We had been told Don would arrive early the next day, so there was little sleep for anyone. I left Sydney knowing that the next time I saw my husband he would die soon after. The events of this last day haunt me. Don dies many times in my sleeping and waking dreams. That we are all still sane, or have the semblance of sanity at least after the horror we had all been through, is a testament to our individual strength. It would have been so easy to go mad.

Just before Don arrived home, the doctor and Palliative care nurse arrived and he spoke to Melissa, Alison and me about what was going to happen to Don. He described events which we might find distressing, which might happen. He told us that Don's face may go a bluish colour. That was when Melissa ran out of the room in tears. It was just too much for her. She'd been so strong and always arrived at the hospital with the largest smile on her face and all her own little private jokes for her dad. She had travelled the long road in Sydney with Don and I and had seen things much more horrible than anything the doctor was describing. This was the final straw for her. She fled the room. My poor kids. She'd seen things at that hospital which no daughter should see happen to any parent, especially one as vulnerable as Don. Alison stoically stuck to the chair, feeling no less shock, just reacting in her own way. Obviously the GP had no idea what we had already seen. How could he?

Veronica and another sister, Joan, arrived back at the house just as the ambulance brought Don home. Veronica later described Don's arrival, with all of us on the driveway, as like a scene from an El Greco painting, with long wintery shadows and shades of dark and light.

Then the doctor broke the news that the ambulance officers were demanding to take the ventilator back with them to the Sydney hospital. Veronica described it as cheap, old and clackity. He allowed Don ten minutes and then began to disconnect the tubes. The ambulance officers were hovering around, obviously pressuring the doctor to give Don's ventilator to them. The only explanation that would cover these actions is if the doctor believed as did Alison that the ventilator belonged to the Air Ambulance and would be needed by them. Alison explained that this was why she did not act, because she believed that it might be needed for an emergency. Although appearing normal I was beyond any effective action at this time. I felt like I was floating and nothing was real. The family will never believe that there was not one spare home ventilator in the whole of NSW that Don could have used. It wasn't exactly state of the art equipment.

I thanked the doctor via email shortly after, because along with all that happened there was great dignity and Don died peacefully. I have no problems with this, it is truth and truth is important. Without the doctor being there this would not have happened and we are always going to be grateful for this.

Things that were actually happening quickly seemed to be happening ever so slowly, but as slow as it all seemed, it was as if there was an inability to act.

After the ventilator and ambulance left, Don indicated he wanted his toothbrush. He had it put into his palm-band and he scrubbed his mouth for ages as if trying to get the stink and taste of that place out of his mouth. Then he indicated he wanted the wrist name band and every bit of tape and evidence of the hospital off his body, which we did quickly. He expressed disgust with these reminders and he was probably at that time the most lucid and clear-headed person in the room. Don had a fair tolerance for opiates because of his pain levels in the past decades, so the morphine in his system at that point did little to that great and sharp mind.

Our old red kelpie Thorn came over to Don and put his big head where Don could pat him. We'd been apart from Thorn for over five weeks but somehow that dog knew. He was so still and quiet, which was unlike him, because he usually barked like crazy when people came. Later when I realised I couldn't hear or see him, I called, expecting him to be in another room. Just the gentle thumping of his tail in the corner of the room let us know he was still there. He was keeping his own vigil; there is no doubt about that. Sadly, this lovely old dog recently died at home in my arms, his duty to our family done. That's how it felt.

Don wanted to look at the girls for a long time and I would see him looking into their faces. He wanted me to be in front of his face so he could see me and we had a last kiss which will have to hold me until... when? I moved into position with my hand under his neck and let the girls be at each side of him. I wanted them to have that precious time.

Then he did something so Don, it still makes me smile. For years he'd been worried about my eldest sister being too thin. It was the family joke that if you were cooking you had to wait until Veronica was outside before you put any butter or oil in. He had a special spot in his heart for Veronica and the pair of them used to often stir me about how much suds I put in the washing and how heavy-handed I was with just about anything. I called it generosity. Veronica had had a dreadful few years prior and he cared about what she'd endured. He asked Melissa to get something for him. She thought he wanted milk so she bought him some. He shook his head and then was able to make us understand he wanted butter. We were all puzzled, but if he wanted butter, fine by us. Melissa bought it in on a spoon. Ali clearly remembers Melissa's running in with it, *"with her funny run, you know Mum, head out, bottom out"*. Melissa thought it was for him to eat, but he indicated to give it to Veronica. She said *"No, no"*, and we all chorused, in an old family joke, *"Eat it Veronica, eat it"*. We all laughed so much at that. For a dying man, it was a pretty clever way of saying something complex which he wouldn't have been able to get out verbally.

Don wanted dearly to be sat into his wheelchair after the ventilator was removed, and Melissa, Alison and I knew why. He wanted badly to be able to have a last look about his home. That's all. Because the chair wasn't at the house when he arrived, however, this simple last wish became impossible, and by the time it did arrive Don was not that far away from death. He was relieved when it was finally in the room, but accepted as a reality that it was too late for him to be able to be put into it. At such sad times small things like this are more poignant.

Don was with us awake for two hours, then went into a sleep and died about 9.30pm. He died with much more dignity than was ever shown to him during his time inside the NSW health system. He died with our two daughters close to him, and my hand tucked up under his chin. I remember him squeezing his chin down on my hand for ages after he last closed his eyes. Melissa, Alison and I had been intently watching his chest rising and falling as Don's breathing slowed. Ali noticed his breathing begin to become irregular. She gave his chest a little pat and off he would go again for a little while. Everyone was so still. The breaths stopped.

And then no more.

It was just over. He was gone. My 35 years of love, fun, wicked delight and companionship just went. My hand resting under his chin began to cool. I was disbelieving, even after all we'd been through.

Those of us who have lost people closest to us know what I felt, what I feel. That has no part here. I couldn't even cry, really. The doctor came and went.

The house was overfull of people. Everyone there held love in their hearts for Don and him for them. An intense feeling of peace settled like a velvet layer over all in the room. The feeling was so strong for me, it felt as if the room had become more crowded, not with angry noisy chaos, but with love-filled mothers and fathers, sisters, brothers, angels. I felt them in that room, the room I sleep in nightly.

One moment he was in the centre, the centre of a love-filled room, warm and human; the next just gone.



Although Don had given me express directions that he was to stay home after death for some few hours, I was pushed by someone who overstepped to call the undertakers. She pushed by telling me things like that Don wouldn't look too good in a short time. I had no experience of death this close and to save the girls distress I acquiesced. I regret this to this day. It was bullshit. He could have stayed the night at least. It was winter. People should back off and not push people who are in the shock of grief. Decisions are made, and things are done and were done that night which we have regretted since.

The undertakers came for Don too soon after his death, there was no rush.

Some Statements From Family and Friends

Before the chapters which describe the fight the family has undertaken to achieve justice and expose the deplorable state of care my husband received under NSW Health, it is important to introduce some statements made by family members and friends who visited Don in the Sydney hospital. Melissa visited every second day. She observed many events which still cause her pain. Alison visited in the early days in ICU and then the last. She has been struggling with her own health since 2002 and we both asked her not to stay, especially once Don became infectious. She was saddened by this, but she was our “researcher”, spending hours every day trying to find out what was going on. It was very hard for both of them.

Veronica and Jackie also have statements of the events they witnessed. My other sister Joan was in the same situation as Alison, being in remission from breast cancer, so we advised her not to come to Sydney. Rod, Don’s nephew, wrote his observations, which are telling. Friends Carmel and Neil made statements too, all of which go to back up what I witnessed and Don endured.

Melissa wrote

It’s hard to know where to start. So much happened to my father on a daily basis. It numbed you and I was unable to stop it or make it better for him. Any time I tried to question what was going on I was met with a brick wall. No answers; only vague talks with doctors who at times were extremely confrontational. Especially towards my mother, which shocked me. I often wonder if the situation had been reversed, how they’d react. When I look back it breaks my heart. I wish we could have done things differently, but the damage had already been done thanks to an operation called a Pleurodesis which we had no prior knowledge of and which was performed within hours of him arriving at the Sydney hospital. From this point it was one disaster after another.

I can’t remember the exact order of the incidents I’m going to list so I’ll just put them down as best I can. The first day I visited Dad was the Friday. He’d had the Pleurodesis on Thursday. He was in the Spinal Unit in a room with another man. He was agitated and talking unusually. Mum took a photo of him and me together. This is the very last photo of him apart from one taken in ICU. It was also the very last time I was to hear his voice normally from this point.

I can’t believe how horribly wrong things went. I got a phone call from my mum. The hospital had called her about 4am and said to come in immediately. I got there soon after she did. We waited in the ICU waiting room with no real idea what was happening. When I went in and saw Dad I got a real shock. He was unconscious; the ventilator was in his mouth and tied around his head quite harshly – pulling at the corners of his mouth. His arms were tied to the bed. I couldn’t stop crying, not so much for me but that he had to suffer this. He was in this room for a while. I remember The ICU doctor coming in and yelling loudly

at Dad for biting the tubes in his mouth. I can only imagine how frustrating it was to be spoken to like a child and not to be able to say anything.

Another thing I remember, Dad had been given some medication and had a reaction. Mum was there with me. His nurse that day was the harsh English nurse. Clear mucus was all over his face and pillow, and he was cold from it. Because of the tube and also because of his position and the fact we knew he had never been able to properly vomit due to quadriplegia we were very worried that he might choke. I asked this nurse to help us (shouldn't need to). Begrudgingly she came over and did suction. Mum and I cleaned him up as well as we could. He then seemed to throw up a few more times. She got very angry about being asked to help. I couldn't believe it. She was prepared to let him lie in his own vomit and have it in his mouth. I asked her for some towels so we could clean him up. She finally gave him some medicine and told us it'd get cleaned up when the lifters came (in a few hours). Unbelievable. He settled. We kind of cleaned up as best we could which was hard because of all the tubes in everywhere. We couldn't get under properly, although we did our best. I can't imagine how he felt; the taste in his mouth, the smell, and you know how you get cold when your pillow is wet. Poor Dad. I can only wonder what happened to Dad at nights when we had to go home. Things like this continued to happen a lot.

Not long after, we were told to leave the room because of infection. When we came back in I stood next to Dad. He chewed through his ventilator tube and he said clearly on the outward breath looking straight at us, "help me." My heart stopped. I didn't know what to do. We were asked to leave. They put in a new tube and Dad was sedated for the rest of that day. When I went home, I was lost. What could I do? I honestly thought he would still pull through and we would go home. I thought they were still working on what was wrong.

Also at this time he developed golden staph. Dad was moved to another room in ICU, sort of like a cubicle. That was where they put him and where he spent the last four weeks of his life. It was horrible.

We had continuously asked for him to be allowed intravenous Vitamin C. The ICU doctor and the pharmacist had no problem with this but a new doctor, Dr L., who had just come on did, and nothing seemed to be going ahead re the Vit C. So we asked what was happening and Mum and I were ushered into a 'conference' room with the female doctor, another female doctor and a nurse. I can't put down the names of the doctors and nurses because no one seemed to have any ID name tags on so it was hard to know who we were interacting with. Anyway, the main doctor refused to allow Dad to have the IV Vit C, and would only allow 1,000mg a day which is much less than what he usually has when he is well. She also refused the use of probiotics to counter all the antibiotics he had had to have. Consequently he suffered with Candida systemically.

Alison wrote

I never thought for a moment that what happened to my Dad in the Sydney hospital was even possible. I was concerned for him, as I knew he hated the place, but as the procedure was so routine being the lung drain and biopsy I really was not concerned that he would eventually die from the treatment they gave

him. I spoke to him in the local hospital on the day he was to fly to Sydney. It was a very long day but I got to have a chat to him on the phone. He sounded ok but not real happy to be going and a little pissed-off sounding, but that seemed normal for where he was. The procedure was done as mentioned while Mum was driving to Sydney, so when I spoke to her next he was out and all had gone well.

I phoned Dad on Saturday about 11am and he seemed all over the place. He was singing "She'll be coming round the mountain when she comes" which we sang together and "A horse is a horse of course of course / and nobody talks to a horse of course / that is of course unless the horse / is the famous Mr. Ed." He was so impressed that I knew all the words to it too. It was a pretty light-hearted conversation, then he became agitated and confused. He kept telling me about something I had no idea about and he seemed really annoyed that I couldn't understand. It was something to do with CPI indexes, whatever that is; I still don't know. This was so out of character for him. He also said that Lissy hadn't come to visit him the day before and he was upset about it, but she had been there on Friday for some time. I was really concerned. He just didn't seem himself and his voice was puffy and short. I called Mum later to see if he was ok.

It was at about 4:15am on the Sunday that the phone rang. I had a sinking feeling as I woke to answer it. It was Mum hurrying up to the hospital. Dad had had a respiratory arrest and was in ICU. I was in shock to say the least. "What on earth had gone wrong?" was my first thought.

I got to speak to Dad on the phone on the Tuesday when he was taken off the respirator. He had bitten through the tube and I was talking to him about him eating yoghurt and giving him a stir about biting through the tube and he just kept repeating over and over, "It was awful, Ali, it tasted awful." It made me chuckle because he sounded a little like he was trying to make light of the situation. I tried to let him go a few times because he sounded so tired. And he was like, "Yeah I might go and rest," and Mum was like, "No Don, you keep talking," and he was like, "OK" and then he was happy to talk again and he told me about ten times in a row, "I love you". Now when I think back I think he knew what I didn't.

Andrew and I came to visit on the Wednesday as he'd had another arrest on Tuesday. It was very surreal when I turned the corner and saw him hooked up to all this machinery with his eyes closed as he was heavily sedated. It was such a sad sight but a part of me was still certain he would recover. "He's my Dad, he will pull through." At the time to think the worst was possible seemed unbelievable. I stood by his bed and touched him wherever I could get my hand in. He roused when the nurse was brushing his teeth. Lissy, Mum and I were there and he had such a big smile on his face when he saw us. It was a beautiful sight to see him awake. He had his eyes closed and Mum was saying, "Ali needs a hit," and he lightly hit me on his left. Then she said, "Lissy needs a hit," and he did the same to her on his right. It was so nice to see him reacting and playing with us as he was. It made me happy for it was in this moment that I realised he didn't have brain damage. We were uncertain if he had suffered some brain damage from the respiratory arrests. It was a big deal to know that he was still himself. He wasn't awake long, nevertheless the moment was still a special one and then he fell asleep again from the medication.

On this visit Melissa, Mum, Aunty Veronica and I were asked to have a conference with The ICU doctor. It was supposed to be informative. We were supposed to be told Dad's condition and what was actually going on. This was what we had been after and we were about to find out. We were taken into this room and we brought out some paper and pens to write down something! So he began talking and it wasn't anything. He asked if we had any questions and Melissa began asking a few. His reply to each of one of them was, "That's a good question but I don't know the answer, do you have any other questions?" It was said in a jovial sounding voice like it was something to laugh at or was funny in some way. I was pretty angry and I said, "Well, what can you tell us?" I think that stopped him dead, the smart arse bastard; I just wanted to slap him! The information was nothing of any substance. Then he asked us what Dad's life was like at home and what he did with his time. He also asked if he would be able to live that life with a tracheotomy in place or be on a ventilator and also had he spoken of his thoughts of being kept alive on a ventilator? Mum said they had actually spoken of it and he had said he hadn't wanted to be kept alive on one. The talk was not very clear. He had some agenda, I imagine, but it seemed very self-serving because we came out feeling like we learnt nothing. We were not told anything and his attitude was pretty poor, to be honest. I am not saying it would be any easy job to speak to people about their loved one's conditions but all that is really required is the truth and even that seemed too much to ask.

I spoke to Mum about five or six times a day from here on as I was living in Melbourne. I had been unwell myself for around four and a half years so it was decided upon by Mum and Dad that my visiting there any longer would be a really bad idea were I to catch any of the heavy duty super bugs in the hospital. The next few weeks were a torture and I couldn't help. I wanted to be there so badly but realised that for me it wasn't a good thing and Dad would've been so angry. When we were told about the procedure that had been done called a Pleurodesis we were all very confused as to why this procedure had been done. Mum, Lissy or I had heard nothing of it. We had understood he was having a biopsy and a simple lung drain. I was straight on the net researching what a Pleurodesis was. It was told to Mum that it was a "standard" procedure; but from my research it had so many implications that should have rung alarm bells in the admitting specialist's head. I mean, I found out in two hours of online medical site searches information that stressed the fact that someone in my father's condition is not a suitable candidate. How many years do they study for? I also found something that at the time seemed very relevant, it explained that people having undergone a Pleurodesis could experience an inflammatory response to the talc and that this inflammation caused them to go into respiratory arrests requiring them to be put onto a ventilator and that they were unable to be taken off. The simple fix for this was to administer cortisone injections to reduce the inflammation in the lungs so that the patient could once again breathe on their own. I have to say that when I found this information I thought that I had found the cure and that they would give it to him and all would be well. I remember phoning Mum with this and she and Lissy were both very excited. Mum spoke to the doctor about this and she was informed that they had already tried this. It was a letdown to think that it hadn't fixed him already. Later though we learnt that they

HAD NOT given him ANY CORTISONE at all. This always stood out to me you know because who knows, it may have helped, or eased some of his suffering.

The doctors were daily telling Mum that they were waiting for the biopsy results; they took sputum samples and were taking much blood for testing daily. We were told they were looking for what was wrong; not that he would never recover no matter what they did. I believed he would get better. I prayed a lot and felt like I was living in a movie. Nothing felt real, time was a blur, nothing sunk in. I tried to do as much research as I could and I spoke to two doctors I know about what was happening to get their advice. They gave quite a lot, most of which the hospital decided was not appropriate or as the doctor put it, "not on my watch." Well, what an awakening that you can't even decide to give yourself vitamins when you are so unwell. I felt helpless from here and Mum felt helpless there too, I know. How could this happen? I know now looking back that they had been lying to us from the beginning. They hadn't put any preparation into the procedure they performed and so when it went wrong they covered their tracks. It would be easier to see that they were lying to us if one had been emotionally removed from the situation, but we all loved him so deeply. The fact that they can lie and make you believe that there is hope when there was none is such an inhumane and cowardly act; very inhumane to Dad because he knew he was dying and wasn't able to die because they wouldn't admit they'd stuffed up, and we had hope he would live because they didn't tell us otherwise. According to them the truth was privileged information that they somehow thought in some sick and twisted way we didn't have the right to know. It was a cruel five weeks for him and for us. I thought about him every minute of the day. He was my last thought at night and my first thought in the morning.

Then Mum phoned and told me Dad was going to be flown home to die. I can't remember what I thought. I think some part of me knew but I hadn't thought it for very long, if that makes sense. I did a quick pack, bought the tickets and was up in Sydney Tuesday night. I came to see Dad straight away. He was in ICU Isolation, which felt like the bowels of the hospital to us. It was so nice to see him he gave me a big smile as I walked around the corner. Oh dear, I miss that face as I remember it now. He let me warm my chilly hands under his arm as I always had cold hands back then. He looked at my hands later as I had them resting over the rail of the bed. My hands are slim and get veiny looking when hung like that. He looked worried about them and asked about it. He was worried about my health; it was just like Dad. He was dying and he was worried about me. Andy told him I was eating heaps of food, big breakies and pork chops, my favourite dish for the month. He smiled and laughed a bit and seemed more at ease about it. Wednesday I was there the whole day and spent quite a lot of time with him by myself. Dad seemed really thirsty and had drunk a whole lot of water. After that he seemed unsettled like he was experiencing a lot of pain, he pointed to his tummy. I went and found his nurse who was not in the ward. She had a look and couldn't work it out. He had a tracheotomy in and it was incredibly hard for him to sound out sentences. He seemed to want me to go for some reason. The nurse quite rudely said, "I can't understand you." I remember it because he was getting a little panicky and he wasn't feeling good and it was increasing. The tone in her voice was so callous and unsympathetic. Did she think he was trying to make it

hard to understand him? I said, "Let me have a listen, I am good at hearing him." I heard EVERY word. "You have to get out of here, I am going to be sick all over the place in a minute, you have to go." I told her and she asked me what he took for nausea. Luckily I knew he had Maxolon and told her. He was pretty happy I heard and in a strange way I was feeling like I'd helped him even just a little bit. He calmed down and was happy to have me stay. He didn't want me to leave; he just didn't want me to see him get sick everywhere. The rest of the time we spent alone together. He was very tired and he was cuddling his yellow pillow the whole time and I was playing with him a bit. He looked so exhausted and he kept dozing off. He'd open his eyes see me there and give me a broad smile and chuckle then doze off again. So I played a game with him and said, "I need to rest too," (a quote from a classic Mackay home movie called 'Don Rock', where Dad played the role of Edie. His performance in this movie was by far his greatest work.) So I put my head gently on the yellow pillow he still had clutched to his chest and we played the open and shut eyes game smiling each time we looked into each other's eyes. It was very sweet.

I spent some time with him that night too and brought him a photo of Judy and Jeanette Mum had stuck to the wall. He had a lot of photos in there and they must've helped him a lot. I made sure I said all the things I could think to say. I told him how great a Dad he is; how sorry I was that I hadn't come home more these last few years and how much I loved him. He mouthed "I love you" back to me. I wanted him to know these things. I felt that they were the most important things to have him hear. It was hard for me to walk out this night. He had given Andy a huge smile when he left, he was happy to have seen him there. I told him when I left, "I will see you at home tomorrow morning."

Back home in the next day, we waited, Lissy, Mum, Veronica, Andrew and me. More people came throughout the day and night. Joanie drove down from Queensland. It was a bit sad as Dad's departure time kept getting pushed back. He was supposed to be here in the morning and it was such a beautiful day. It was a comfort to know that Jackie was with him all day through and thankfully there ended up being room for her on the plane too. Dad arrived home at around 5-5.30pm. It was great to see him and I remember giving Jackie a big hug. I was just so grateful that she could be with him on the plane trip home. Dad was very aware when he arrived home. He was put in bed by many helping hands. There were two palliative care nurses and Don's doctor was there as well as the two ambulance people. They had not been able to locate a ventilator that Dad could use here and we were told they needed this one back straightaway. He only had it for around fifteen or so minutes. It was very brief and nowhere near long enough for him or us. The doctor removed the ventilator tube. I was frozen, numb. I saw but couldn't react, I thought the ventilator belonged to the air ambulance and that they could need it for a rescue or to transport another person who may need it. It turns out, though, that this was not the case. He could have kept it and this will be a regret that I did not fight for him so he could keep it a bit longer. Had I been myself at the time and not frozen with shock I would have been able to do something. It was a very surreal evening.

Dad brushed his teeth for some time no doubt wanting to get the filth of the hospital out of there. I tell you he had so much control over what he was doing

and spat straight into the cup so neatly for a brief moment you kind of thought, hey what's going on here, maybe he is alright. A sight I will never forget was him brushing his teeth with such precision and determination. The time was short, shorter than one would think. I remember a funny thing he said to me. I was on his right side and wedged in by people when he began to overheat. I asked Mum who was closest could she grab a washer for him he said, "Get off your arse and get it yourself." I was in shock but amused, it was so clear. To be honest it was not how he would normally speak but it was how he felt when we were lazy as kids. He was surrounded by many people who loved him. His brother Ian made it to see him, Dad threw his arms open when he saw him. It was so great for Dad that he got this.

Melissa and I got to spend some time with Dad, just the two of us, and it was a special time I will never forget. I remember Dad saying, "My Mum said I was too hard on you girls." Lissy replied, "No Dad, we turned out fine; you are a good dad and we love you very much." We both gave him a big cuddle on either side. It was incredibly sad because that was the last hug I was ever to share with my father and it was a beautiful moment, one that I cherish.

I left the room for a brief moment to go to the toilet and grab a glass of water. I am not sure what happened in that time, whether he just deteriorated or if the nurse had administered more or a new medication, but Dad had his eyes closed when I came back. He was alive but his eyes never opened again from this moment on. We all sat around his bed; Lissy was on his left side holding his shoulder; Mum was on his right side with her hand under his chin, as he was sitting up in bed upon his own request, and I was on the right too with my hand on his chest close to his heart. Everyone else was around the bed, very close too, touching him where they could. Time felt like silence. I could hear people talking but in my own self it was a stillness. I felt hot but freezing at the same time. My skin was numb. He began to breathe slower and slower. I had my hand on his chest and I was gently giving it a rub which sort of encouraged him to breathe when I did. I remember saying to Mum, "Mum look at Dad." As he took his last few breaths complete silence filled the room. Then Mum let out a painful sound and cried. We sat around him for some time and he still looked alive just like he was resting.

It was a bittersweet end to all he had endured in his life and especially in the last five weeks of it. He should not have had to suffer like he did and he should have been able to pass naturally and at home in peace many years from now when it was his time. It is a treasure, however, that he made it home and got to be in his own bedroom surrounded by so much love in his final moments.

I love my Dad very much and as I recollect all of this my throat aches with so much sorrow. I feel that I have yet to grieve enough to justify all that Dad meant to me. All that he gave to me; all that he was to me and all that he will always be to me. I carry a part of him with me always. I can see him in my own eyes and hear him when I speak sometimes. I would like to forget that he suffered as he did, I would love... rather it is those who saw and knew the suffering who feel it now. There should be justice for the unjust treatment he received, for the blatant lack of respect for the sacredness of life. They showed him no mercy as his family stood by powerless to help him. I remember Dad for who he was. I have many vivid

memories of him laughing and being the great man that he was. They cannot take that away.

I love you Dad and miss you every day. May we meet again in the next life as we have in our lives before this.

Veronica wrote

I have known Don since he and Therese met in 1972. The way he handled the restrictions that life had placed upon him was awe-inspiring. I never heard him complain but I've heard others complaining to him about their lesser ailments. He was generous not only to his own family but also to his extended family and to the community. He and my sister, Therese, were inseparable, not only because of the nature of Don's handicap but because they truly loved each other. He was a self-educated man with good business acumen who could talk about a broad range of things. I find it hard to express the admiration that I have for the way he led his life, suffice it to say he was my hero and will be my inspiration for the rest of my life.

We all have to die and I know there is no justice in the allocation of just how we will meet our end, but a man on Death Row would have had a gentler end than my poor brother-in-law.

I was there when the subcutaneous cannula was inserted into his abdomen through which he was to receive the drugs to ease his passage into whatever does or doesn't wait for us on the other side. Well, not hard to find things to cry about! The thing that made me cry inside – but hopefully I didn't really cry, I can't remember – was when the nurse came to put in the cannula that was to deliver the morphine. He didn't want her to do it but wanted me to do it. I was complimented by his confidence and perhaps it would have humanised it for him, but it wouldn't have been possible. Aside from not being registered in NSW and not being employed by the hospital I wouldn't have been able to see through my tears. I had cried almost non-stop since I heard from the social worker that he would have a ventilator to get him home, and this was a huge coup for her, but then was to have it removed so that he would die shortly after. I feel an awful sense of failure about this episode and the preceding hour before when I was alone with Don I just couldn't turn off the waterworks. His fate was so unfair, totally unwarranted, and couldn't have been imagined in our worse nightmares. Time stood still in that little room. People guilty of heinous crimes are meted out executions by some countries but here there was no crime. In a cruel twist of fate, the innocent was to die as a result of the lack of care of the admitting specialist, the man whose job it was to fix his problem.

After that encounter Don's inevitable path to his plot in the cemetery was sprinkled with pain, indignity, misunderstanding; staff who were efficient and gave of their best but also staff who were lazy, arrogant and uncaring. It was all so unnecessary. And all played out against the backdrop of this diseased major Sydney hospital.

Here are some memories that are particularly vivid for me:

I worked in the Haemodialysis Unit at this hospital in the mid 1980s and although I encountered bullying there, the hospital was clean and seemed to me

to be providing a competent service. This time even before I went inside I was struck by the faded, mottled dark grey/brown of the exterior. Whatever the surface had been made of was not meant to last. I thought: "Despair all ye who enter here!" The décor of the exterior was continued inside. Dark little entrance, a little shop, lifts to wards, passageways leading to more dinginess.

No effort to present even a façade of cleanliness and efficiency. The Brisbane hospital, where I work, which presents exactly that, looks magnificent by comparison. I couldn't believe how dirty the windows were and was amused by a collection staff had started in the canteen to get the windows cleaned. This disappeared rather quickly. No doubt management were shamed.

On the notice board en route to the canteen there was a poster proclaiming that millions were going to be spent on a new research building. "What," I asked myself, "is the use of this if basic cleanliness isn't being observed so that patients are well enough to benefit from the work of researchers?" That is, if the research is meant for them and not just for the aggrandisement of the few and the lining of pockets! Maybe a few crumbs for the riff raff. Couldn't the people who were responsible for this poster see what a comparison they were inviting by placing it in that spot? People around weren't saying, "Wow!" but, "How come they don't spend some of that money round here?"

The cardboard-lined lifts were the jewel in the crown, however. They had been like that for the whole five weeks Don was in hospital and who knows how long before and for how long after. I passed some rooms in which there was piled-up furniture. From memory, Don's ward in ICU was a trip back to the 80s. Nothing modern here; no computerised entry, the machinery and furniture was old and of course you couldn't see out of the windows.

If you were a visitor to for any length of time you would be driven out by its ugliness, dirt and clutter to the better life to be had across the road, where the nurses' car park used to be, which was the salubrious Private Hospital. Before the public hospital had sucked my energy I was planning a series of comparison photos of the two hospitals to put on our staff notice board. I got some done in the flower and marble bedecked foyer of the hospital for the better folk but really had no heart to photograph the pauper hospital. I wonder if the admitting specialist would have pleurodesed Don if he'd been a resident of the marbled halls?

Family Conferences! Better than none at all, I guess, honeyed words to lull you into a false sense that it was going to be ok. Everything was under control. In the beginning we were told the plan, the investigations that had been done... but really they didn't know what was causing the effusions. The ICU doctor ended by saying that maybe Don wouldn't make it out. At this stage we were still grappling with the mystery of effusions. The second conference was with a blonde female doctor. This conference seemed to go really well and we felt here was someone we could do business with. The worm turned when Therese wanted to ask further questions and she was told we'd had our conference. Therese's request to have high doses of Vit C included in Don's medication was met with a curt rebuttal. At this time what harm would this have done?

By the time of the third conference I had moved from effusions to why did Don arrive in Sydney with a moderate right side pleural effusion, have a Pleurodesis

and after the intended cure, a respiratory arrest followed by an exacerbation of his original condition? The issue became what was the link between the Pleurodesis and the aftermath. By this stage too we had witnessed attempts to get Don off the respirator fail, due to CO2 retention. We had lots of questions for the admitting specialist but failed to be worthy of his attention at this stage. We got instead the interviewing specialist whose English was very difficult to understand, consequently the ICU Sister answered our questions the best she could.

This doctor's name is on Don's consent for the Pleurodesis. It was signed about 10.45pm 11/04/07, Don would have been exhausted by the trip from Port. I can't imagine that he would have been able to fully understand the interviewing specialist's English as he explained the risks that Don, a quadriplegic with limited respiratory function, would take having the procedure.

One particular vivid memory for me was when they were trying to see if Don could be taken off the ventilator. He had to wear a skullcap with a harness across his face. I think Don could breathe spontaneously but the machine delivered mandatory hyperinflation at regular intervals. He was clearly struggling. His tongue was out but curled under – looked like a lizard's tongue. Therese was alarmed because this was the type of breathing he had before his original respiratory arrest which was ignored by staff. The nurse said he was trying to speak! His breathing rate was up to 50 BPM and then that nurse turned off the screen. We could no longer see how fast his breathing was. She had told us he was trying to talk, but blood gas proved otherwise and he was put back on the ventilator.

This set me off seeing Don's encounters with medical staff in terms of a Matthais Grunwald painting "The Temptation of St. Anthony". The defenceless one tortured by the imps tied down, straining at his bonds, trying to get rid of that vile-tasting tube. It was like seeing a vision of hell made even worse because it was done to one who was blameless and who we loved and had to watch in pain because we didn't want him to be alone. But it felt we were also in the uncomfortable role of conspirators.

This image came up when I returned to the hospital in his last week. The social worker was gleefully telling us that Don was to go home the next day with a respirator. Great! I thought. But I hadn't been told the rest – that then the respirator was to be taken away! This was delivered in the same tone. How lucky he was! The hospital sets him up to die with tortures beforehand but they will grant him his wish. What else could he choose but to die within a few hours of getting home? Lucky man! I was alone with Don when the nurse came to put the subcutaneous cannula in to deliver the last drugs he was to have. Don wanted me to put it in. A friendly touch perhaps to put the last needle in. The nurse did it with robot precision. No doubt she felt the strain of what she had to do. Then amazingly, after all this, a nurse was going to give Don Lasix but I saw they had taken his IV fluid away. I am a long time renal dialysis nurse and know that the results of this would have been torture for Don. It took quite a while and the intervention of a doctor to get the fluid back up.

This last stage of it all becomes an El Greco: long shadows; long, pale faces; Don's long, grey cap; the clackity old respirator. Jackie, dressed in black, seemed

to have lost weight on the trip with Don. He seemed to have become paler and thinner beyond description.

If Don had died naturally, I could have remembered him sadly and fondly. As it is, I truly try not to think of him as I cannot get past the picture of him in Intensive Care, and the surreal scene of his death and the pictures leave me feeling poisoned as if I watched an unjust execution and did nothing to prevent it. Almost as bad is the helplessness I feel at being able to do little – even nothing to relieve the grief of my sister. All I can say to her is to take comfort in the knowledge that she married the best and had a love that some of us never experience. He was an exemplary man who was ennobled by his misfortunes. All of us were made better by knowing him. Then to have to stand by helplessly and put our trust in the system (because there was nothing else) that had caused his unnecessary and rapid decline and then to see that system when it had finally admitted that it couldn't save him or had no further use for him put the boot in again and offer him the choice how he wanted to die has made me, at least, feel less.

Neil wrote

Neil Thrift wrote the following not long after Don died. He emailed this from Germany where he was seeking treatment for his cancer and seeing relatives. Sadly Neil died in 2008.

Don Mackay was a true gentleman, a man who under great difficulties healthwise worked tirelessly all his life for the betterment of the community, he also performed his role as husband and father we would suggest better than most men.

What my partner and I experienced while visiting Don in ICU can only be described as frightening to say the least. We found this ward to be in an absolutely filthy condition. Not just a one-day situation but walls, floors, doors and equipment etc., all suffering a lack of cleanliness and hygiene obviously over a long period of time. Would you expect, in an ICU ward especially, a hose having fallen from Don's breathing machine onto the floor, to be picked up and replaced back into the machine without any cleaning, not so much as a wipe? It happened. Would you expect, in an ICU ward especially, staff while still working eating pizzas and drinking, at the same time walking between each other's patients?

Would you expect it to be possible for a nurse to work caring for a patient in an ICU ward one on one to be unable to speak understandable English, either to us or other staff, some of whom just laughed and treated it as some sort of joke? Some joke! Would you expect wardsmen who also clean the toilets are also are the patient lifters and turners, some of whom do not wash hands between lifting patients, even those in isolation? Believe us it happened.

We wonder why nurses mostly no longer wear name tags, so as to be easily identified. Is there a message here? It was as Don's wife said at one point of this journey of disaster with Don, "It was not just Don but all of us who were being traumatised, just watching the situation unable to help." Terrible the complete lack of care and compassion shown to Don, with most staff showing no interest in him at all. We have never experienced anything like it, it was so extreme to be almost unreal. Was there something, someone or some special problem we were not aware of? There must be some reason for this unnatural behaviour by so many staff.

One occasion while visiting, Don was again in big trouble breathing, his tongue was moving in and out rapidly under the mask. I must point out that Don always had his arms tied down. The nurse on duty asked us, "Do you think he is trying to say something?" Therese then pointed out to the nurse that his breathing rate had visually risen so dramatically and also referring her to the breathing monitor which confirmed our observations. To our horror the nurse immediately SWITCHED OFF THE BREATHING MONITOR telling us in a 'mind your own business' voice to stop watching everything. She did nothing, until less than twenty minutes later Don suffered yet another respiratory arrest. How was this possible? How could we know what was happening but nobody else? Urgent answers are needed. Someone has to do something soon before more people die in this hospital.

Again on a visit to see Don we were present when there was a meeting of doctors and nursing staff at Don's bedside. Therese has asked so many questions without receiving any straight or positive answers. Nothing as to what they were doing, except waiting on blood tests. Blood tests for weeks and still no answers?

Still no answers after weeks as to what they were actually doing or treating for Don. Still no answers after weeks as to just what the actual original problem was that left Don in this desperate lingering condition. We are all aware now and we also know now just why Don Mackay died. But just what has happened to the next of kin, Therese, being fully informed at all times? In particular of Don's medical condition. Therese was bedside 12–14 hours daily or mobile phone available to be into the hospital in as little as ten minutes at night.

Certainly, looking at the papers available regarding this procedure, to us lay persons it does not make sense. The admitting specialist appears along with many other doctors and nursing staff to have combined to cover up this absolute tragedy. All this at the expense of Don's life, which can only be described as five weeks of torture.

Carmel wrote

I have known Don and Therese Mackay for 31 years. In the time I knew him, he was funny, articulate and cared for his family and all who knew him.

I arrived at the house the day before Don left to go to the Sydney hospital. He was cracking jokes and was full of hope and love for his daughter's coming wedding. I took my usual treat, a cake. But he was not eating today; he was pale and nervous about the flight to Sydney and the stay at the hospital. As I was looking at him I felt a great sadness, that this might be the last time I saw him. I remember thinking why the hospital here could not have performed this simple procedure and this made me angry and still does to this day. I was not to know at that time I would also be seeing him at the Sydney hospital.

I arrived in Sydney and went straight to the hospital to see Don. The exterior of the hospital is old and in need of repair. All the windows are extremely dirty. At the Intensive Care Ward, a nurse told me to ring his ward number from the internal phone in the waiting room. The waiting room was full of old tables and chairs, bins full of rubbish and again extremely dirty windows. While waiting I went to the toilet. It was dirty, paper all over the floor. The sink was putrid.

I had not been in a hospital for years so I braced myself for what I might see. Nothing prepared me for what I saw. Don lay in bed with tubes everywhere and a ventilator hose in his mouth. There were no windows in this room; it was like a box with half one side open. There were no pictures, no hints at comfort and most of the time, rubbish on the floor. I hoped he knew I was there. I talked to him about old times, the wedding, anything. I would try to read to him and comfort him. The days I was there he was distressed and uncomfortable. If it had not been for Therese his wife and me doing small things for him, I do not know how much worse it could have been.

One day I was there, he had his arms tied down; a fly was hanging around his mouth. He was distressed beyond anything I could do. Once I asked the nurse for help but she did not have a clue. She showed him a card with drawings on, so he could point to what he wanted. She untied his arms and he was throwing his arms about because he was beyond being able to point. It made me sick in stomach to see a wonderful man reduced to such appalling treatment.

I was told he had a one on one nurse at all times of the day. I never saw anyone there all of the time. The ones I did see, some were sensible, some very dismissive, some downright rude and treated him like an idiot. One day I had to go across to the chemist which was in the private Hospital adjacent. There was a doorman in uniform who opened the door for me. Inside gold framed pictures, comfortable armchairs and bright colours on the walls. It made me feel sick because one minute away there was such filth and despair. Has our society become so callous it only matters how much money you have and that dictates your treatment?

I have been told of all the mismanagement of Don's care. I can't comment on that because I was not there all the time, nor am I a medic. But I do know what I saw and it was not right. None of this should have happened; he only went to Sydney for a lung drain. He ended up with collapsed lungs and a body full of infection from the treatment he received.

His last days were filled with distress.

I was told that when he returned to his home, he was Don again, be it for a short time. I hope nobody ever has to go through what Therese, Melissa, Alison and the family had to and I hope this letter can come near to stopping this happening again.

By telling you this, I want you to know that the man I saw in that hospital bed was not the Don I knew. The Don that I knew for 31 years was funny, articulate and cared for his family and all who knew him. He was an active member of his community and worked many hours for local and state affairs.

A Life Ends and the Fight for Justice Begins

Ah well, it's all done now. I have beaten myself up for two years on why I didn't do this or that. I have lain awake for hours trying to sleep, unable to figure out why I didn't move faster and more decisively before his death and after it. No more. The demons of my nights have driven me so that many times after an hour or two of sleep I'd be up and writing down things that had been haunting my dreams rather than lying in bed unable to sleep and unable to stop the crying. The events I have relayed previously are just the tip of the monstrous iceberg which was his time being injured and brutalised inside that major Sydney teaching hospital. That the girls, Veronica and I, and Don as well, didn't go mad is to our credit. Months later I finally admitted to myself that I needed help and sought grief counselling. It helped explain some things such as why there are still huge gaps in my memory. Maybe that's a good thing at this time.

My life was never in danger as it is when soldiers go to war, but I have an idea how it must feel like when they come out of the savagery of war and are expected to function inside what we call normal society. I feel as if I have been in a war zone. My best friend and the only man I have loved deeply, apart from my dad, was killed in that war zone. He wasn't a soldier. He didn't volunteer. There were no medals pinned to his chest and I doubt that any soldiers were as brutalised for as long and in the manner he was by their own side, or by the enemy. That society as a whole and the legal system accepts the above, and has made it impossible to get justice through the system – that is why I am writing this. I have tried every single avenue I could think of to make those doctors and nurses accountable for what was done to Don. Not only does the system paid for by you and me from our taxes not work to investigate, it actively works to absolve the rotten system from any responsibility.

The girls and I know what was done to Don. We don't have to prove anything. What we want is for the doctors and nurses who treated to be accountable. We want the many managers and administrators at and responsible for this hospital who allow it to run at such a desperately dirty and chaotic level, where there is little continuity and notes are illegible, to be accountable. We want the bureaucrats in the NSW Health Department who have allowed such filth and chaos in our health system to be accountable. And we want the NSW State Government, the Premier and Health Minister in particular, to be accountable.

My advice to them is, better accountable in this life than in the great beyond.

The Records

Everyone left after the funeral, one by one, until one day I was the only one left at Craggy Island, apart from Thorn. The old, gentle and very patient kelpie was my great comfort. I cried and I cried. Don was everywhere and he was nowhere. We had known that this time was coming for a few years, and he would make his jokes about it. God, we came so close so many times I didn't need reminding, but

that was his way. He was no coward and to be with him on his level I had to be no coward also. I don't even need to mention what Don would have done if I had been the one killed in the manner he was killed. It was a killing and no pretty, 'correct' words will ever change that.

I have no doubts there will be a bevy of excuses and bullshit trotted out to cover every sentence I write. I know how the only body in NSW which is set up by the government to investigate complaints such as mine works. The Health Care Complaints Commission has declared all of the above to be 'acceptable', using taxpayers' money to do so. But I'm getting ahead of myself.

The first thing I did when the dust settled was to begin the process of obtaining all hospital and medical records. It took a bit of work as I had to word the request very carefully, aware that if I left out one relevant word, that part of the records might not be sent. As it was I had to chase up both hospitals for the X-rays, some pathology reports, flow charts and the like. For a lay person as I am, it was hard to know what was left out and I'd hazard a guess that I don't have all of it. Not to worry. Veronica would say to me that something should show up on the Spinal flow chart and then I'd realise I hadn't been sent it. It was a trial and error thing.

Melissa was quite brave when I asked her to go and pick up the huge bag of X-rays and scans from the Sydney hospital. She said it was really hard going back inside and that she felt sick. I wish I had someone else in Sydney I could have asked, and will always be sorry that she had to go through this. The funny thing was that they handed over to her all his X-rays and scans without even asking to see some identification. She could have been anyone. I had rung than and told them someone was coming to pick up those records, but I could have been anyone. I could have been a doctor, or a bureaucrat, a lawyer... anyone. It is too easy for such records to just disappear. Luckily ours hadn't.

The peculiar thing, and costly too, was that Don's doctor wouldn't just send out the records as did the two hospitals. I had to pay my solicitor to write a letter and it had to be verified that I was indeed Don's wife and next of kin. I don't know why he was so fearful. I wasn't the least bit interested in him but needed those records for continuity. As it was, this kindly man charged me 50 cents a page for them, at least 30 cents a page more than the hospitals had. He also tried to charge me for sending me someone else's records, which tickled my fancy. But that's not out of the ordinary, as the Sydney Hospital also sent me two other people's records with their home addresses and phone numbers on them. Don't believe for one minute that your medical records are confidential. I received records from three places and two of those places sent other people's records.

The next months, in between solicitors' visits and tying up the many threads of Don's public life, I wrote and wrote. I wrote four main documents, which I still use. I have learnt a lot more since then but I thank God I got going as soon as I did. One of the documents, 'Document B', lists many studies which show why a Pleurodesis should never have even been considered for Don, including one of the admitting specialist's own statements to a medical journal. He had to have been aware of the work of Dr Richard Light and others who were beginning to show alarming statistics and side effects of Pleurodesis. Dr Light said a Pleurodesis should never be done on anyone who isn't terminal.

Don was given a Pleurodesis after only minutes to take in what it might mean to him, if he was informed at all. There is no way Don was told of the actual risks. With the air ambulance nurse with Don until 10.25pm, during which time she's told me there was no doctor present, and The interviewing specialist having signed Don up by 10.45pm for a lung drain, biopsy and Pleurodesis, it is clear to me that Don signed a consent form not fully informed as to the real risks. It would take much longer for anyone, let alone a quadriplegic, to consider the implications of such surgery, and then weigh it all up. Impossible. There was no informed consent.

The Pleurodesis was done at the maximum dose of 10g of talc, although this is changed later in typed notes to 7g. It was done while Don still had fluid in his pleural lining. It was done at the same time biopsies were performed. Don had been unable to fully expand his lungs since 1982. No matter what the admitting specialist says, Don hadn't been able to take a deep breath since 1982. It should only ever be done, if at all, on a fully expanded lung with no fluid and with a smaller dosage of talc '*As he had such marginal respiratory reserves, he was incapable of ventilating after Pleurodesis.*' (ICU Specialist). It is stated in the literature that it is dangerous to do a Pleurodesis at time of biopsies.

Don would never survive this operation and the surgeon and cardiothoracic team should have, and I believe would have had a fair idea this was the case. I believe they realised he was in trouble a day after his operation and this explains their attitude.

At the end I have provided a list of the studies and articles that Melissa, Alison, Veronica and I used to back up what we already understood had happened to Don. All were available to the admitting specialist and his team; indeed, he is the author of one of them.

By September 2007, I had collated all the documents. At that time there was a big stink in the media about some shocking things which had happened inside this hospital. The one I recall best was when a young woman, was forced to have a miscarriage in the public toilets in Emergency after she had tried without success to get A&E staff to help her. People were rightfully shocked at the callousness of her treatment and along with other similar cases it made the news.

Sometimes things slot into place, seemingly at random, but I'm not so sure about the randomness of events lately. Before the hospital began making headlines, I'd gone to our local paper and Andrew Stoner, the National Party Leader and Member for Oxley, with what had happened to Don. Don had a reasonably high profile locally because of his activism and also because the pair of us were prolific "letters to the editor" writers. We were always passionate about the things we believed in. Made us one or two good friends but also many who didn't like us. I had no real idea of the number of people who held Don in high regard until after he died.

At midnight on 26 September 2007, I finally completed assembling four large ring binders, each identical and each with a photo of Don on the front cover and the family on the back cover. Each page was inside plastic to make it more presentable and easy to handle. It had been a huge task and the whole lounge room floor had been covered with pages for a day or two. There is likely to be the odd page with a big dog print or two on it, but it was done. I addressed one copy to the Ombudsman,

one to the Health Care Complaints Commission and had two spares. The next morning, Andrew Stoner's office rang to ask if I could possibly be in Sydney at Parliament House by early afternoon, that same day. The synchronicity of the two events was astounding. One day before and all I'd have had was a big bundle of unassembled paper.

As it was, I had a spare copy to leave with Andrew Stoner. I don't know if he will ever know how grateful I was for that call. Sydney is not very interested in what happens to people outside of Sydney, but here was a chance for me to draw public attention to what was done to my husband. There was a ticket at the airport and a car to Parliament House. I called Melissa who was living at Coogee. She met me there and we spent the afternoon together, and Andrew Stoner asked his question in Parliament, as recorded in Hansard:

Mr ANDREW STONER: *"My question is directed to the Minister for Health. Given that the Minister assured Mark Dreyer yesterday that the terms of reference of the inquiry into (hospital name) I will be extended to include any matter he wishes investigated, will she now give the same assurance to Therese MacKay, who is in the gallery and whose husband died in May, so that she can get answers to the serious questions she has about his treatment at (hospital name)?"*

Ms REBA MEAGHER: *"First, I extend my most sincere condolences to Mrs MacKay. I am sorry that we meet under these circumstances and not outside this Chamber. The inquiry's terms of reference relate to the service provided to women presenting at (hospital name) threatening miscarriage. However, if Mrs MacKay has concerns about the standard of care that her husband received – by all means I will welcome and support her making a reference to the Health Care Complaints Commission for a thorough investigation."*

(Hospital name has been removed from the above question and answer)

That's all Reba ever did. She passed it all to the infamous HCCC, which can be relied upon to do sweet bugger-all. Reba Meagher was however finally shamed into broadening the terms of reference of the Hospital inquiry. Now the inquiry was for all and sundry. It was a useless whitewash, as it turned out, but more about that later.

The Daily Telegraph and a Sydney radio station covered what happened to Don. It was such a hyper day. I did the radio interview on my mobile phone as Melissa drove me back to the airport and have forgotten which radio station it was. But they did an excellent job.

Over the time in between then and now there has been a fair amount of media coverage, much of it spurred by the actions I have initiated, and some by the actions of others, such as Andrew Stoner. I now began to include him and the Opposition Health Minister, Jillian Skinner, in whatever updates and responses occurred. I had a list of media people, health reporters and the like, which I have kept up to date, because I knew that to get a grasp on what really happened to Don you had to understand much more than one horrific night, or two. You had to be able to grasp what it meant to have five weeks of dreadful days and nights and for many this is too hard. We live in a time of the quick grab, read quickly

and forget quickly. Many of us over 50 grew up in a slower time, and actually had a whole childhood before we had television. Our age group battles with the join between the older ways of our parents and the faster ways of the young adults. We are sort of in the middle because we know the value of what our parents had, but have been swept up with all the speed.

But I was determined I was going to do everything I could think of to make sure that those who hurt Don, or turned a blind eye to his suffering and abuse, would know I was around and was not going away. I hope that every time a story appears which has anything to do with Don and this hospital, those responsible experience a cold chill of knowing that this is one they are just not going to bury. Don is not out there buried in the cemetery, underneath the flowers. I have no doubt as to where Don is right now, and when I wake up at 3am with the idea to start another prong of the campaign and it's laid out so perfectly that all I have to do is write it out, I have no doubt at all that there is a God of compassion, a just God, and that Don is within the sphere of that great love. He doesn't suffer now.

A nun once told me when I was a kid that heaven was a blessed state of knowing God. That means knowing and understanding all truth and outside of linear time which is just a construction of our human mind. One morning I woke up with my arms wrapped tightly around myself. The dream I had had was a gift. The few people who knew Don before we moved to our home town 1976, when he was in his early twenties, knew what a golden-looking man he was. He had golden blonde long hair and a beard slightly darker. He had the best set of shoulders I have ever seen apart from my own dad. There was nothing more wonderful than watching him out on his surfboard, totally connected to the wave he was on. He took such pleasure in life, in all ways. In my dream Don was lying back near a waterfall on a large flat rock in the sun. It was like a place we'd been to near Cairns in 1973. His arm was behind his head. The sunlight shone on him but he seemed to shine as well. He turned and looked at me and there he was again right inside my heart, golden and shining. I carried the feeling of being blessed by this dream for days, and still do. It doesn't worry me that not everyone will agree with me on my experience, if what others thought of me mattered much I'd have never done anything worthwhile in this life.

What I think is important is that it's not just me running this campaign for justice. Along with the huge emotional help from my daughters, sisters and my friend Carmel, I have felt at times this amazing strength and boost of energy just when I was at my lowest. I prefer to think of it as heavenly inspiration. Others can argue about clusters of cells agitating as I sleep and producing order, but I'm with the poet William Cowper:

*But oars alone can ne'er prevail
To reach the distant coast;
The breath of Heaven must swell the sail,
Or all the toil is lost.*

As I often admonish myself when I get off the track, "Back to things concrete, or let's have some concretion here please, Therese." The actions I have undertaken and the bodies I have contacted with my submission and complaint have been the

Health Care Complaints Commission; the Ombudsman; the Hospital Inquiry ; the NSW Coroner; an internal Hospital Inquiry; the Peter Garling Inquiry into NSW Public Hospitals; and the Independent Commission Against Corruption (ICAC). I have created, launched, run and completed a petition for a full inquiry into Don's death and attended when Mr Stoner lodged it in Parliament; and now this book, which is the biggest thing. But I wanted to show that I haven't just launched into this with a sense of grievance without exhausting every single avenue open to me before I did.

In a wise society, where life really is sacred, I should not have had to do even one of the above. Along with Melissa and Alison I should have been allowed my time to grieve, comforted by the fact that, as with any other wrongful death in Australia, the authorities would seek information, appoint lawyers and medical personnel to sift through that information, not in the biased and adversarial way the HCCC does, but honestly trying to look for a cause, or causes, of death. If cause was found then I should have the right to expect that those people were charged in the same way anyone else would be charged, and called to account and that all involved in Don's death would have to give evidence under oath. We have become too used to there being one law for everyone else but no legal redress apart from hiring your own lawyers to sue hospitals and doctors. But if you go that way, you risk losing control of the situation and being forced to settle, go home and shut up. It's all about the money then. Nothing gets changed and the bloody rotten system becomes even more entrenched.

Doctors and nurses and politicians and bureaucrats listen up; we are not interested in the money and that's why we are a danger to the disgraceful system which exists and which allowed my husband such a sickening end to what was an exceptional life. I would have been prepared to write a legal contract to say I wouldn't sue if the doctors and bureaucrats had had the guts to be honest with me early on. Doctors and hospitals wonder why people are so angry and why so much security is needed inside hospitals these days. While there are some violent people out there, a large part of the reason has to be the arrogant manner in which people are treated by too many staff. I cheerfully would have liked to smack a few of them in the face, or tell them where to go, but was acutely aware that they could always call security. Wouldn't that be something in a sane world, being able to call security to protect our loved ones against their brutality and callousness?

In between that September day at Parliament House and the day I gave evidence myself at Parliament House two months later with Melissa alongside, I spent many hours trying to understand the records and contacting as many people as I could to get as much publicity as possible. I am quite shameless about this, because I know the HCCC has been pretty useless all round, and apart from the Coroner's office there were not too many other official avenues open to me. Any chance I could I would ring talkback radio and I have to give Grant Goldman of 2SM a big bit of praise here. Whenever I have rung in about what was done to Don, he has given me a fair hearing and I feel has been supportive. His talkback radio show is on from very early in the morning, for those of us who rise early, until 9am. He is one of the media that I keep informed, because I know in my heart that there will be an end to all of this and I know that what was done to Don, once fully understood by people, will help

to change some things for others. I have to hope that knowledge of the depth of the suffering they inflicted upon one human being, for so long, will wake up those good doctors and nurses so that they no longer compromise their ethics by protecting and covering up for those who are bad doctors and bad nurses.

I had always thought that doctors had a maxim of 'First do no harm'. I think that the Cardiothoracic, Spinal and ICU doctors might do well to have this tattooed onto their forearms so as to remind themselves of that simple precautionary and humbling set of words. I saw some of them I recognised from ICU at the inquiry into the hospital.

On the afternoon of 16 November 2007, it was time for the patients and relatives to give evidence. Most of us had sat through hours of doctors talking about how hard done by they were, and how shoddy the equipment was, all of which may be true. What surprised me, though, was that when it came time for patients and relatives to give evidence, those doctors all left. There were doctors there who were directly responsible for sections of the hospital we lay people were to give evidence about, and if they had really wanted to find out what was wrong with the hospital and their care of people, they could have stayed and listened. We had had to sit through all their evidence, because we needed to be there in case our time came up. In a sane world, patients and relatives would be the supreme people in any hospital and the doctors and administrators would want to listen to what their wishes were, to what they had to say. But no, all of them from what I could see were gone by the time hospital victims and relatives gave evidence. If I am wrong here doctors, my apologies, but it was clear to those of us about to give evidence that a huge bunch of medical staff left when their time to talk was over. I find their behaviour reprehensible. They may have actually learnt something rather than just sounding off on what they already knew.

During the hearings, one large older senior doctor sat down behind Melissa, another lady and me. When he realised he wasn't amongst the clutch of doctors on the other side of the aisle, he got up abruptly, banged into the back of my chair, and almost knocked Melissa and the other lady out of theirs. He didn't even turn around or apologise or see if he'd hurt anyone, but moments before he had broken down into tears over his "drawer full of letters from grateful patients." What a show of emotion. If he had really cared about those patients he should have stayed and listened to them and their relatives.

There was publicity around this inquiry, and a follow-up article in the Sydney Morning Herald, and then that was about it. The paper the report was printed on was wasted as the whitewash by the committee with a couple of dissenting reports was smothered. The NSW Labor Government, which was at that time under Morris Iemma with Reba Meagher as Health Minister, should be thoroughly ashamed. The aim of the inquiry was just to quieten the media until they lost interest – and it worked. The report was released just before Christmas, which is a perfect time to bury reports like this. For those of us exhausted by the grief of having to give evidence, having to relive and bare our souls to people, most of whom didn't give a damn, it was a horrible experience, as well as a pointless one. I came away feeling like a two-dimensional person, as if I had left my heart on the table for the committee members to dissect.

Our first Christmas without Don came. There was just Melissa, Alison and me, and Thorn. We wanted it that way. We couldn't have anyone else with us, because we knew we'd have to pretend. As it was it was special because we tried to do what we normally did. The funny thing was that each Christmas we would do a family photo, all dressed up with tinsel and red and green dresses or whatever. The girls would spend ages doing their hair and the years of photos like this are our treasure, our testament. Each year I'd set the camera up on a tripod and the girls would leave a place behind Don for me with them on either side. I'd press the button and run to get into place. Last Christmas, we did this again, just us three. When I pressed that bloody button and ran, we all got confused. Don had been our main prop. He was our main prop in so many ways. It was sort of funny and also terribly sad. We all realised and laughed. No doubt that Don would have been pleased. He totally adored being centre stage.

Don's death was no way like any death you might expect after illness. We were left suffering from post-traumatic shock. I fear my heart will never mend and when I consider the legacy that this hospital has left the three of us, I feel cold and desolate. I never believed anything like this was possible, much less happen to Don and us; after all he'd already been through. Don and I were not fools. We knew we were on borrowed time. It was not the death which has us like this. It was the cruelty, the duration of that cruelty to such a frail man. We do not, cannot and need not ever try to comprehend why human beings, who you might walk past in the street, can become so immune to fellow suffering that they allowed and covered up what was done to Don with full approval of the NSW Government.

The Reports from the Sydney Hospital

On Christmas Eve, if my memory serves, I received the drafts of two documents the hospital produced to explain away what was done to Don. They were both authored by the Clinical Governance Officer, Dr H. I received the official signed copies a few days later, after Christmas. The first document was a letter and the results of the internal inquiry into Don's treatment and death. The second was the so-called Root Cause Analysis (RCA) which examined the root causes of what went wrong and a timeline of how to fix these problems.

I didn't show the girls until after Christmas because the contents and the soft shoe shuffle language used by these bureaucrats made me furious and I wanted them to have as nice a Christmas as possible. Then we prepared our response.

Our response to the Internal Inquiry and RCA document generated the Sydney Hospital – Hospital names have been removed

Dear H,

Just after Christmas 2007 we received the final copy of the hospital's internal inquiry into my husband and my children's father Don Mackay's treatment and death, after surgery performed inside the Hospital. Along with those close members of our family who have now read these two documents I have to admit to at first becoming extremely angry at the tone of the response, and also alarmed at the language used and the glossing over of what are serious mistakes and dangerous flaws in the treatment of my husband which we claim directly caused his death. On top of that there are things which have been added to the response which are blatantly untrue constructions and I will address these.

As well the response does not deal with most of my original complaint and issues raised in there. I question just how well it was read and understood as whole areas have been left unanswered and unaddressed.

1. The documents go to great lengths to push the view that a Pleurodesis is the required treatment for any fluids in the pleural lining of the lungs.

I know of many people who presented with the same that more often the treatment of fluid of the duration my husband had it is conservative and involves just drainage and biopsies to determine cause.

When I spoke with a doctor (who had been my husband's Spinal Specialist for some time) after Don had died she was shocked to hear he had had a Pleurodesis. She had thought he would have been home and well, and said that all that was needed was to drain the lung, do the biopsy and then send Don home if the Biopsies showed nothing (which they did after 5 weeks of testing). She said to me that if the fluid built up again it would have been easy enough to just drain the lung again as it was a very slow build up and that considering his state of health and the dangers of interfering with his lungs, because of Quadriplegia this should have been done.

The Pleurodesis was not only unnecessary it was considered by this doctor potentially dangerous and so it proved to be. We would like to see the medical data and success figures regarding Pleurodesis.

2. **Cause of the fluid build up.** The family is coming to the thinking that the cause of the slow fluid build up was misdiagnosed from the beginning and that had it been treated and diagnosed properly Don would be with us today. In mid 2006 Don was first diagnosed with a small Pericardial Effusion. Not too long after that he developed a chest infection which was serious and hard to shake. This was the first of its sort in 25 years as a Quad. From the Hospital's Inquiry we have now been told he also had a Mitral Regurgitation. We were never told of this while we were at the hospital. We should have been. The X-rays from the hospital, done over the 5-week period often mention an enlarged heart. We suspect that the fluid was from the heart conditions and that once the misdiagnosis was made it had a life of its own and no one thought to query this. As mentioned in the whole 5-week period in ICU he had test after test done and there was found no bacteria, virus or any other cause of the fluid build up, from the fluid itself.

3. **In the internal hospital inquiry they said, "There is a clear medical distinction between complications that follow and those directly caused by a procedure"**. I agree with this statement but not in the way they imply. There is clear proof that Don's Respiratory Arrest and Acute Respiratory Distress Syndrome were directly caused by the Pleurodesis and the mishandling, mistakes and negligence which followed this dangerous (for him) operation.

Don had developed a very slow build up of fluid and had been at home for the four months we definitely knew something was wrong. Although tired and breathless from this there were no events and we handled his growing weakness waiting for his doctor to finally do something. The long wait was dreadful for us and caused my husband to suffer unnecessarily.

But not even one day after the Pleurodesis (12 April) he began developing the symptoms which we now know were leading to his respiratory Arrest (15 April). This is all noted in even their poor notation, which only recorded bits and pieces and few times.

On the day of his surgery (12th) I arrived from home at 1.30pm and he was sitting up in bed pleased as punch and looking forward to getting home by the end of the next week in plenty of time for our daughter's wedding. He recovered well from the anaesthetic and was very clear headed and so pleased to see I had arrived safely. Soon he began drinking water freely and began to eat as he was so hungry. It all looked so good.

But that night (12 April) just before I went to the room I was staying in he said a few things which were out of character and were not linked to anything. It worried me but as we were both really tired I just put it down to that. That was the first sign of what was already well under way in his lungs.

It stretches credulity for them to suggest that the ARDS which they now deny although it appears many times in their own notes and the respiratory arrest were unconnected to the surgery.

4. What they say that their understandings of my major concerns are which is dot pointed on page one, is flawed and puts words into my mouth which are not true.

- a. Where they say, "Mr Mackay had a Pleurodesis operation that may not have been strictly necessary". I never said this. Our stance has always been that it was not only unnecessary but also dangerous.
- b. Where they say the "operation failed to cure his recurrent pleural effusion and in fact triggered a decline". Our stance has always been that the effusion was not recurrent but had reaccumulated as it had never been drained fully. We feel that it didn't trigger a decline; we believe it caused his death directly.
- c. They say, "The decline became irreversible due to failure to recognise Mr Mackay's deterioration, despite your having flagged concerns". Our stance has always been that we could not understand why they acted with such negligence towards such a sick man and with such bad attitude in that he was "blanked" by nursing staff in spinal. I did not "flag concerns" I was almost beside myself going from nurse to nurse over the two days prior and even our daughter in Melbourne who spoke with her father at 11am 14 April, could tell how sick he was over the phone such that she rang me back terribly upset. He got progressively worse when common sense should have had him becoming progressively better.
- d. I agree with, along with many other things.
- e. Yes agree with this and would like to know to whom the home ventilator belonged. Was it the Sydney Hospital's or the Air Ambulance?

5. They continually call it a recurrent effusion. Dr K a local heart Specialist called it a reaccumulation. Also they "assumed" (their words) that Don had been under a Cardio Thoracic specialist in locally. Why would they assume this? The only contact at all with any Cardio thoracic person was through a doctor (not Don's but a locum) who was left to care for Don after the two senior Doctors of the practice, went off for a month each. The locum had no knowledge at all of Spinal medicine and after a few calls to him we realised he had no understanding. He rang a doctor in a neighbouring centre a Cardio Thoracic Specialist and it was he who first mentioned Pleurodesis although we were never told about this. This specialist had never met Don and would have had no idea about his current or any state of health as the locum had no idea himself. It was too much for him, because it was specialised.

6. We would like an answer to what was the bizarre haste to operate on Don such that none of his history was understood. This was dangerous. Why not wait? Why did not one doctor, the interviewing specialist, the admitting specialist or the anaesthetist, put the brakes on because of the lack of information accompanying such a sick man?

Why was no spinal physician consulted? This is standard procedure. (pg5)

7. Did the interviewing specialist and the admitting specialist see Don's recent (local) CT scan or did they see a report? Did they see anything at all?

8. The interviewing specialist held a conference with my sister Veronica and I later on in ICU. He was so hard to understand when he attempted to explain issues that my sister asked the nurse if she could explain /translate what he was saying. How could Don who would have been exhausted after the extremely long day, arriving by air ambulance at 10pm, either on a trolley or bundled into bed, how could Don have taken in anything about the mechanics and side effects of Pleurodesis? It is impossible to believe he would have understood for the reasons above. The interviewing specialist was almost impossible to follow and a Pleurodesis takes some explanation if you have never heard of it before. If explained properly all the side effects should have been listed. No way could Don have taken all this in, processed it and then signed up all within half an hour or so, late at night and exhausted as he was. It was NOT an emergency.

9. Why can the interviewing specialist not recall what he told Don about the Pleurodesis? There should be a set and mandatory explanation of the Pleurodesis, approved by the surgeon which contains a full explanation of the procedure and all the risks and side effects including the real danger of ARDS. Every person should be fully informed and told the same things, plus because of Don's Quadriplegia which was of a long term and his marginal respiratory reserves the real risk of ARDS should have been explained to him. I have known Don for 35 years and I know he would have wanted to think about doing something, which could cause what actually did happen. He was very careful when it came to his lungs and general health. To not have it explained is negligence. Why is there no record of what information Don signed to agree to the Pleurodesis? Where was it written that Mr. Mackay knew he had been transferred to Sydney to have a Pleurodesis? How was this reinforced what documentation states this? (pg2) Where was it written so that the admitting specialist came to believe (assumed) that Don had full knowledge of the Pleurodesis prior to his transfer to Sydney? One would think there is a format of information that they MUST provide to obtain consent.

10. A trivial correction here but important to us. They say I was Don's "primary carer and advocate" I was his wife for 35 years and his only carer for 25. We were each other's advocates. That's how we worked. I require to be known as his wife not just his carer. I deserve that and he would want that.

11. The Patient's representative said that "you (I) were not expecting a Pleurodesis to occur, and were anticipating a more graduated process of drainage, biopsy and then, if necessary Pleurodesis." Where does this statement come from? I had never even heard the word Pleurodesis so how could I anticipate "**a more graduated process of drainage, biopsy and then, if necessary Pleurodesis**"? That is a made up by someone and for what reason. Don and I thought and were told nothing to the contrary that he was to have a lung drain and Biopsy. If he said I said the above sentence then he is wrong. I never ever anticipated a Pleurodesis. How could I? I had never heard the word? Why have they included this? (pg2-3) He stated on both pages that Donald and

These were aware that the Pleurodesis was anticipated this is a false statement and needs to be addressed!

12. **A Comprehensive Care plan** should have been mandatory between Spinal and Cardio Thoracic. Why and how was this neglected? Why did Cardiothoracic assume Don had seen a cardiothoracic specialist locally? There is no notation towards that. It is unprofessional, unscientific and negligent when dealing with life and death issues to assume such things. How did they arrive at this false and ungrounded assumption? When did they assume that Don had had the Pleurodesis discussed with him in the local hospital? There is no notation of this discussion in the hospital's notes. Why was there no full assessment by Spinal Specialists and Cardiothoracic specialists pre operatively? To not do this on someone, anyone, but someone with Don's complications and considering the dangers of failed Pleurodesis is negligence. The internal hospital Inquiry says, "It would have been wise". That is offensive to us, Don's family but to him most of all. Why did the treating team at the Sydney hospital think Mr Mackay was under the care of a thoracic surgeon? Where is this information? Why would they assume further thoracic review was not required when Don had seen NO thoracic specialist? The AMA and hospitals must have some mandatory rules they are meant to follow in this way.

13. **Corrective Action** while any correction is positive all the above should be compulsory for all doctors in Australian hospitals. The Sydney hospital has shown a gross lack of duty of care.

14. The **admitting specialist had not met Don until in Theatre it appears.** He had no hands on knowledge of his real situation re health pre operatively. He was the first Cardio Thoracic specialist to actually see Don apart from the brief signing of the consent form by the interviewing specialist, if that's what he is. What quality of surgeon or specialist would do non emergency surgery on any patient at all, but especially one with all the problems Don had, without making sure that a checklist of mandatory steps were followed and in place. To not do so is shows a breach of duty of care. How could a team of trained specialists EVER assume that further thoracic review wasn't required? Why would they presume their work was already done for them by some fictitious thoracic specialist? One would think that they would value human life and do the right and mandatory preoperative tests required to properly and safely treat their patients

15. **Pleurodesis is not the standard treatment for all lung fluid reaccumulation.** I happen to know that in Royal Brisbane many patients with fluid build up are treated conservatively as Don's Spinal Outreach doctor expected Don to be. If there is a known cancer or Asbestosis then this issue changes, but Don had no diagnosis and there is no reason to believe a Pleurodesis was standard for him. He was not a standard patient. **See the admitting specialist's own article in the references at the end of this book.**

This is a quote from that article, “We conclude that regardless of the risk for dissemination, the severe local inflammatory reaction incited by talc may be sufficient to cause a fatal systemic response.

16. We still stand by the statements we made about the dangerous way the Pleurodesis was done. It is a known in the US that it is dangerous to do it when you do biopsies. That is in the literature we have provided and we stand by this.

Why was ungraded talc used **given its known risk of ARDS?** (pg3) Is it cheaper?

17. Why were they all so ready to assume (that word again) Don’s deterioration was post op anaesthetic, when it had all the hallmarks of a Pleurodesis reaction? We are told over and over how standard this operation is, how come neither Cardio Thoracic nor Spinal recognised the classic signs of Don’s failed Pleurodesis and reaction? ARDS is a known major complication of Pleurodesis which you say is standard treatment for all fluid build up in lungs, a common occurrence with Quads, so most in Spinal and Cardiothoracic would have been used to treating those who have had this operation.

18. It was clear to me that Don recovered from the anaesthetic quickly because of how he was when I first arrived. One would expect a natural progression from a bad reaction to anaesthetic to a better state of health not the other way around and it was obvious that he was rapidly getting worse, but nothing seemed to make them go into any effective action. It was only in the early hours of 15 April when he was close to respiratory arrest that they took any serious action but then it was too late. We consider this gross negligence by Cardio Thoracic and Spinal.

19. Why did Cardio Thoracic order Don to be sat up in his wheelchair knowing (as they should have done) that for Quads, because of the mechanism of their breathing it was well known to be much harder work for a Quad to breathe sitting up than lying down, even when well. Even the heart Specialist in the local base hospital noted this. Cardio Thoracic who claim Pleurodesis is standard for fluid build up even for Quads must have known this. He suffered dreadfully because of their negligence, this suffering still haunts us.

20. Why were Don and I not told about the mistake made in theatre and continued in Spinal concerning the suction of Don’s lungs? The suction was ordered to be at 3 KPA (Kilopascals) but because as the Sydney hospital claims a transcription error by theatre staff meant that Don’s lungs were suctioned at 31 KPA for almost 24 hours till the next morning when a nurse in Spinal at 8am discovered the mistake. Surely the admitting specialist should have told us of this. Surely also he should have checked after surgery that all the systems were correct and being done properly. I am under the understanding that doctors should provide full disclosure to patients and or their next of kin and that this is a legal responsibility. This almost never happened in this hospital.

It is outrageous to think that the KPA could have been misread so hugely. Could this have caused both his lungs to collapse as is recorded? Fluid to build up more rapidly? ARDS? We were never told during Don's whole time about the condition of his lungs at the time of admittance to ICU. Why not?

21. **Why were Cardiothoracic unable to see the signs of impending Respiratory Arrest and ARDS** when Don's fluctuating SATs (oxygen levels) and increasing disorientation made it blatantly obvious what was happening was a classic inflammatory response to a failed Pleurodesis which ended in Don's death five weeks later?

22. **Why did the Spinal Intern "assume" Don's agitation was due to hypoxia?** Did he not know the signs of ARDS and impending respiratory arrest which can occur after what we are told is such a standard operation to relieve fluid buildup in lungs? Surely this common operation would mean that all interns would be aware of the serious side effects of respiratory arrest after Pleurodesis? Don's reaction was a classic reaction as anyone who reads the literature (see Document B) will know.

23. **14 April Medical records note that Don was "stable", although previously he had been "muttering to self, disorientated to place and person".** This statement beggars belief. This was the day I spent almost harassing nurses to the condition of my husband who when forced to sit up in his wheelchair became seriously distressed and breathless and very confused. He asked me to help him clean his teeth multiple times in an hour period. His tongue was visible being forced in and out of his mouth in what looked a painful and involuntary manner. This was visible and I had never seen anything like this. He was mouth breathing harshly and the nasal prongs they ordered were useless. They were not overworked as I was caring for my husband, giving him drinks, fixing up things nursing staff would normally do. The sicker he became the worse he was treated. The hospital has not addressed these failings and has made no moves to disciplining the doctors and nurses who allowed all this to happen. I doubt they have any intention of doing so. There was no duty of care shown to my poor husband.

24. **Don arrived at ICU with collapsed lungs.** I was never told this and neither was Don. Why had both lungs collapsed? He only had surgery on the right hand side one. Did the excessive suction of his lungs post-op cause this double collapse? After this his previously healthy left lung filled up with fluid and had to be constantly drained.

25. **"What went wrong?" What went right would be a better question.** In Spinal Ward 7 D, Don's treatment by both Cardiothoracic and Spinal was most unacceptable.

On the morning he stopped breathing he called his my name over a three-hour period, according to his roommate. Why was I not phoned? He was clearly

distressed and frightened! My number was on the wall on a sheet we provided and in his file, and I told the nurses to call if Don needed me. I told them that I was only a five-minute walk away. What reason did they have not to do as I asked? For three hours as he went into respiratory distress he called the one person who had always looked after him properly and they denied him this. The hospital has not addressed this. This is a shocking thing to have to think about for us.

- a. The hospital's claim Spinal was not usually able to deal with issues concerning lungs. This is not acceptable. Don was a patient in this Sydney hospital and the hospital should have made sure he was where he could be to have the best outcome. It is unacceptable to expect us to accept this as an explanation. Spinal should know all about lung issues as so many Spinal patients have serious lung complications. It is not acceptable for the Inquiry to act as apologists for something that should not have happened.
- b. The hospital says "the failure to heed your (my) warning". My warning. What they should say is my multiple warnings. We find ourselves wondering why constantly in this Internal Inquiry issues like this are downplayed. My many warnings especially on 14th April were coming at nursing staff about every half hour. None of them even bothered to record these. I feel extreme anger towards these people. We have a strong nursing tradition in our family and I know that their behaviour was unacceptable. Unfortunately none of them wore name tags, as was also the case with the nurses in ICU. You never knew who you were dealing with.
- c. "Failure to recognise disorientation was due to hypoxia." Why exactly was that the case over a period of days? How do you explain that?

26. In the Action to be taken pg 6... 11,12,13; why is this now needed? Any halfway decent hospital would have had these set in place as a matter of course.

27. Regarding the restraint, securing of tubes and Infection... these issues are raised in Doc C. Infection control in the hospital is a joke. The aprons used in isolation are like bib and brace aprons and Don laid in intensive care for five weeks with his arms tied to the bed, both lungs filling up with fluid constantly, body full of infection, sepsis they called it. He was full of excess fluid. He caught MRSA, that is Golden Staph, first in the arterial line then in his lungs and Klebsiella Pneumonia in his lungs, Candida Albicans all throughout his mouth, in his urine and no doubt in his whole system. The place was filthy beyond words. There was no continuity of care. The internal hospital inquiry has not adequately addressed these issues.

Staff and much of doctors' and nurses' notes are illegible, which made this lack of continuity dangerously worse. The lack of hygiene in intensive care was shameful. Infection control is almost non-existent. In isolation they use a throwaway plastic bib type of apron, which covers only about a third of your body and clothing. Apparently the staph and other dangerous germs do not go on the arms, sides and back of the body. Infection (pg7) Reusing the suction tube by storing it under his pillow and reinserting it into his lungs AFTER

being dropped on the floor seems like a pretty slack approach. Three or four days after this had Klebsiella Pneumonia and Golden Staph (MRSA) in his lungs. This needs to be addressed. The hospital did not touch on the disgraceful lack of proper infection control, which has visibly worsened since previous visits. The place is just filthy.

Why does ICU allow nurses to reuse suction nozzles... to slip them back inside plastic envelopes and put them under pillows for the next use when everywhere else I know about discards that nozzle and starts fresh every single time? Is it cheaper?

28. Speech pathologist. The hospital says her arrival was “premature”... this is a wonder. Considering she arrived a day or two before Don died after his being in need of her for five weeks, this was just another indignity. The speech pathologist came to Don the day after he was told he was dying and tried then to teach him to speak with a tracheotomy in place. This was very thoughtless as were her comments that he wasn't trying very hard. It was not premature. It was too late and incredibly thoughtless. It was just another cruel indignity. She was a horrible person to a dying man.

29. The Hospital says that Spinal's Dr H's explanation for why Spinal would not even co-operate with respiratory after respiratory finally admitted the needed Spinal input is disgraceful. Don was a quadriplegic with lung problems. Should we now advise all Spinal patients who need care not to go to this hospital as spinal will not look after them if they have lung problems and Respiratory is hopeless at comprehending the mechanism of Spinal (Quad) breathing as shown when they ordered Don to be sat up in his chair which worsened his condition rapidly? How is it then that spinal patients with respiratory problems are to be treated if neither spinal or thoracic is equipped to manage their care? I think this is just an excuse for the lack of care given. All staff should be able to recognise respiratory distress! One would hope that even early training of Assistants in Nursing which is six weeks would need to be able to recognise these signs. I did and I am not medically trained.

30. Who did the home ventilator Don was sent home with belong to? Was it Air Ambulance or the Sydney hospital? Why couldn't it be left till Don decided he was ready for its removal? Don's return home, although grateful to have been home and to have him home in his final hours the fact that the ventilator was withdrawn so rapidly after his arrival remains a question. What was the hurry? I believe this ventilator travelled with him from the hospital. Why was there such an urgency for its return? By the withdrawal of this unit they took away his right to choose his time. This should have been his choice alone! At the time I thought we had NO CHOICE as it was the air ambulances and they needed it for emergencies, but they didn't and he did. I would like to find out why this happened. A person always retains the right to decide when exactly the ventilator is turned off.

31. What I am left with, as are no doubt my daughters and sister, are constant flashbacks. I feel I have three levels of seeing at present. What I see in front of me, the world etc., what my mind's eye turns on for me concerning my husband's extreme and dreadful suffering and what was between me and my lovely husband, the thirty five years of good things. Right now the images from the hospital seem to predominate.

The images I still see in my head from that hospital are horrible; there is no other description.

ROOT CAUSE ANALYSIS (RCA) REPORT.

1. **When was it known that he had Mitral regurgitation?** Could this have been a clue or indication that the pleural effusion was from a heart problem? (pg3) We were never told about this. Why not please?

2. **Why was no Respiratory physician consulted until 19 April?** (pg5) Don was in ICU by this time and very ill since his operation 12 April. Also why was no Spinal Specialist appointed to see Don? This beggars belief in a hospital servicing Sydney in 2007.

3. **Why was there limited time for a preoperative assessment?** Regardless of his entry time this should not factor into whether or not a full preoperative assessment is performed. (pg5)

4. **Why was the anaesthetist's review so limited?** (pg5) the hospital says he was "informed" about Don. Did he actually see Don in the hours before the operation as is expected practice in hospitals when patients are visited by the Anaesthetist? There is no record of this. Please explain.

5. **Why were they under the impression he was seeing a Cardio Thoracic physician in Coffs Harbour rather than his local doctor?** He had seen NO thoracic specialist of any kind! Where did they receive this impression? (pg5) How do they keep making mistakes like this even in a report into their own mistakes?

6. **Why was the Pleurodesis procedure deemed appropriate?** Don's Spinal Outreach specialist was shocked when she heard they had given him the Pleurodesis (pg5)

7. **What guidelines was the admitting specialist following when he administered the talc of 10g – which was hand written at the time of the operation but then typed afterwards at 7g?** (This needs more explanation... these things should not happen. What is hand written at the time of the

operation is more likely to be truth. (pg6) In the notes it clearly states that the British Thoracic Society Guidelines recommended a maximum dose of 4g!

8. How was it that 2 RNs and a Dr, plus a 4th RN missed the KPA being at the wrong settings? 31KPA is a big difference to 3KPA. (pg6) Regardless of them stating that the rate of suction didn't impact upon the patient's condition we don't believe them! The hospital's explanation is over complicated designed to confuse. The difference between 3 and 31 kpa is huge. Why did theatre make this mistake and how come the admitting specialist did not pick it up? This was his responsibility as the surgeon.

9. Why did they assume that the referring physician was a Cardio Thoracic specialist? This is negligent and proved to be so.

10. Why did they not do their own testing and analysis first? Rather than try to create blame by saying that they "assumed" or that they were under the impression he was a specialist why can't they say they were just lazy and in a hurry to get the operation done? That his life was not worth the hospital's time to do a thorough preoperative assessment as they should always do!

The hospital have gone nowhere near to addressing the issues we raised in our original complaint (Documents A.B.C and D and statements), which Ms Dowling requested. They have not even gone into the lack of ID of nurses and doctors, the filth, the cruelty and the lack of human rights my husband so stoically endured. They appear to address issues but anything close to the bone they have glossed over such as the big issue of the mistake of suction 3kpa to 31kpa. In my original complaint there are many more incidents which remain unaddressed which led to an increase in Don's suffering and what we can only term as torture.

They have raised more issues than we believed existed and we have to wonder why all the shuffling. What was and most likely is still going on inside that hospital. We raised many issues such as why was there the need for Don to be given four bags of blood in one day when he had no internal bleeding? These things remain a mystery to us.

The family has felt that something very wrong went on inside the Sydney hospital and the receipt of these latest documents from them makes that belief even stronger.

CHAPTER 22

And the Rest of the Fight

And on and on it goes. I think they believe that if they keep putting red herrings in my path I will give up. They've got me figured wrong. I am the sort of person that the more garbage you throw at me the harder I fight. Don and I were both like this. The girls have said on more than one occasion, "Picking on this family! What were they thinking of?" They know. I just wish that they hadn't picked on us, nor anyone else. I've always liked this verse of "The Gambler" by Kenny Rogers.

*"You got to know when to hold em, know when to fold em,
Know when to walk away, know when to run.
You never count your money when you're sittin at the table.
There'll be time enough for countin when the dealin's done."*

That's how Don and I were. I had well-meaning people say to me, "You know, all this that you're doing, it won't bring him back." They don't know. I watched his shocking torture and death and I would not wish him back to this world in any way, shape or form. He deserves whatever relief and peace he now enjoys and I am glad for him. I am entitled to my righteous anger and I am entitled to seek justice in whatever way I can for what they did to him. Others who like and care for me are concerned that I will become bitter and fanatical about all of this. Those people need to know this is not my nature. I am a morning person. Each day is new to me. I walk down the long gravel path at daybreak and marvel at the colours of dawn and the birds paired up flying above my head, the ducks paddling in the dam and the magpies carolling to me. In the first months after Don died I would walk with Thorn out into the morning mists until he too died, in September 2007.

I am a happy little vegemite mostly and I do still believe in the goodness in mankind. I believe that life really is sacred and that there is a plan, but that there is free will in that plan. I believe in angels and their help. So my book is not pessimistic. It's a wake-up call. Not one more person in this country should be allowed to be done to death in the barbaric way my husband was. Not one doctor, not one nurse, one bureaucrat or politician should ever consider covering up with words and fandangle to protect the system which has been allowed to flourish which allows such horrors to happen. They all stand accused by our daughters and me.



In February 2008, I received a brief and useless response from the HCCC telling me that the matters I had raised and wished them to investigate could be listed for "conciliation". I had a big problem with this. According to their regulations, when you have HCCC-sponsored conciliation, what is said inside must remain forever

confidential. Meaning that we could sit opposite a couple of the bureaucrats or a doctor or two for a couple of hours and spend most of that time being talked to. If it's anything like the way conferences are usually held inside the NSW hospital complaints system, they would all go away self-satisfied and we again would be left empty. If we agreed to conciliation, the outcome for us would not be dissimilar to suing them, except they wouldn't pay up. Both ways we'd come away having to shut up and not go public or try for some real justice.

Besides – conciliation? For what they did? I would like to see have to give evidence under oath before a court. I realise that the way the system bends over backwards to lessen the importance of my husband's life and of the unnecessary suffering and death they caused, it's most unlikely that this will happen, but I intend pressing on until I have exhausted all available avenues, and I have a feeling that I will achieve some justice, in a way not clear to me yet.

The HCCC has an odd way of investigating. How it works is that either you or a close relative is injured and/or killed by a doctor, nurse or hospital, or all of the above. After getting the records, and putting together your complaint, you send it to the HCCC. Everyone tells you to do this, no matter who you ask. They are supposed to be the bees' knees. More like bumble bees. The HCCC then sends on your information to the person or people you complained about. After the 'professionals' – these being the doctors, nurses and hospital bureaucrats – have had full access to your complaint and responded, the HCCC then makes its decision, without giving you the same chance to respond to the professionals' claims as they had to respond to yours. Furthermore, whatever the professionals say is treated as gospel. If you are unhappy with the outcome and wish to go further, you are pushed towards conciliation, which seldom works in favour of the complainant. I would recommend anyone who opts for conciliation to take a good bullshit detector with you, because the HCCC and the doctors and bureaucrats will all be talking a language you cannot make sense of. It is never done in your favour and you are always made to defend, although in a rational world they would be on the defence.

The Garling Inquiry into Acute Care in NSW Public Hospitals

Early in 2008, Andrew Stoner's office sent me information about this inquiry and how to ensure I was able to give evidence. I could have given evidence at the Sydney hospital's internal inquiry, but the thought of going back there or even remembering that place makes me feel physically ill. I have spent many times dry retching after unexpectedly seeing the horrible building on TV, although this intensity is easing as time passes, thank God. When I heard the Garling inquiry was to go round many of the public hospitals hearing evidence, I put my name down to speak at locally on 28 March 2008. The day I gave evidence, the local ABC radio station ran a long interview with me and allowed me as much time as needed to tell the story. The copy of that interview has been a valuable resource as it's on CD and can be used to explain things I no longer wish to talk about. Writing this is, I hope, the beginning of the end of relaying what happened. Sometimes when I try to tell people, you can tell they think it wasn't possible for all this stuff to happen, there was just so much of it. Don and I had a lot of respect for an old

friend called Glen Walker, who had been fighting the poisoning of our water supplies with fluoride for decades. He once told us to always tell the truth and know your sources. They have no weapons against that. We used his advice, given in the late 1980s, in going about all our activities. Just tell the truth and know your sources.

I was first up to give evidence that.

After that harrowing experience I was so flattened, I remember returning to my seat and not being able to see people in front of me clearly, until a man called Russell Pilcher called me over. He was to give evidence about his wife who has Multiple Sclerosis, and he knew what it had cost me. You have to be close to someone with severe disability to know the cost of even risking hospitalisation with them. He also has his horror stories. A local TV station was waiting outside to talk to another lady and myself and we both seemed to outsiders to breeze through that.

Out in the car park, I barely made it to the van before I started to shake uncontrollably and great sobs poured out of me. I sat at the wheel wondering how I would get home, and felt so traumatised that my heart seemed to be hammering in my ears. Strangely, out of the blue, Veronica rang me right then. She never rang at that time, and just hearing her voice on the end of the phone, talking me down, brought back some semblance of control. Some time later, actually on the day we launched the petition, I was watching the news and Vanessa Anderson's father came out of that leg of the Garling inquiry. His daughter was killed by the medical negligence of medical staff a little before Don died. The cameras were there. The look in his eyes was horrible. I knew that look, it was how I felt. I knew then that those of us who are the walking wounded of medical error and negligence share the same inconsolable heartbreak. I hope it eases for the Andersons, for others and for us.

The Petition

In the small hours one day in March 2008, I woke up at about 3am which was normal time those days. I was visiting Alison's place. Fully formed in my head was an action I could begin which would hopefully bring about an independent inquiry into Don's death at best, and at least help ensure the authorities were not allowed to easily forget and sweep their dirt under the carpet. I got my notebook out and wrote it all down, knowing if I didn't my idea for a petition would be all gone to mush by the morning.

I wasn't to know that the wording was not precisely correct. Again, being a lay person, I wrongly assumed that if you worded a petition respectfully to reflect what you wanted, and that it was clearly understood, it would be acceptable. For some this might seem naive, but I had seen a few petitions in my time. Not all of them were worded as precisely as I was told by Reba Meagher's office mine should have been. I accept that I should have known to use the word 'Parliament' but instead I used 'Premier'. It appears to me very naive in hindsight. Not to worry, it achieved a large part of what I wanted.

The petition was worded thus:

Donald William Mackay's cruel death cries out for justice.

This time Silence is not dignity.

We, the undersigned residents of and visitors to NSW, request that the NSW State Premier and Health Minister begin a full, independent and open investigation into the surgery, treatment, care and subsequent death of Donald William Mackay, as a result of the five weeks he spent in (hospital name) between 11th April 2007 and 17th May 2007 (the day he died). We ask that those responsible if found culpable then be subject to disciplinary action. Our reasons are briefly – a hospital Internal Investigation into Donald Mackay's hospitalisation and death, signed by the hospital's Dr H. who in writing, admitted many failures in Donald Mackay's care; such failures, which we believe led directly to his death after five weeks of unimaginable suffering.

No point in being a shrinking violet when they've just killed your husband. My mother gave me a holy card not too long before she died, and it sits framed on my bookshelf. It says 'God grant me the Serenity to accept the things I cannot change, Courage to change the things I can and Wisdom to know the difference.' She didn't give me that so I'd just sit back and let injustice be done to those I loved. Mum had some mighty battles of her own and she was a very brave woman. If I can just have half her courage I will be leaving a great legacy to my daughters. My battle for justice for Don will have an end, I know that. Mum's was never to end until she died. She knew that as well. That took real courage.

I emailed the petition to everyone on my email list and posted it to everyone in my address book. I urged them that even if they only had their own name on the paper, to mail it back to me. Each name was important. Along with the petition I included a two-page summary of what was done to Don, most of it based directly on the two internal hospital reports from early January. One old lady who vaguely knew me from my childhood, who lives way out of town in the bush and is now in her mid-90s, posted hers back with just the one name 'Esme Symington'. A young homeless man called Scott went to the trouble of posting a copy back. Sometimes it was those papers sent back with one name on which meant the most. As I said, each name was important and I meant that. Their signing was recognition that an injustice had been done to my husband, and they were putting their name to this. Every one of over 2,000 names was like this and the authorities should be aware. People are extremely angry at what is going on in our hospitals.

When I announced to the media that we were going to launch the petition outside NSW Parliament House when both Houses were sitting on 2 April 2008, I had to figure out a way of making four of us – me, Melissa, Veronica and Carmel – look like many more people. Although Don was easily able to pull crowds together for anti-privatisation rallies in the past and more recently an anti-fluoridation rally, he and I had become a bit isolated in past years, partly from choice and partly because of the precarious state of his health. So when it came time to launch the petition there were just the four of us. I didn't quite have the confidence to ask for help and was used to doing things my way, or our way. So to make it stand out I spent days constructing large posters. I think we had over thirty. I put many large pictures of Don on them asking questions such as 'What the hell is going on in (hospital

name)?' and the like. I also constructed a series which portrayed Don's life from a baby till his death and many people stopped to follow this along from beginning to end. Then I had them all laminated and strung together with cable ties. This was some project. Packed into my suitcase and on the plane with Carmel, we were off.

I knew that the posters would be effective when I laid them out on the floor for Melissa and Chris to see at their home. Veronica, Carmel and I could hear how impressed they were. That pleased me because I am not always as confident as I make out. So there we were at 8.30am stringing all the posters along the fence outside Parliament House. The security guards even gave us permission to attach them, as long as we took everything away at the end. It was a heady day and I don't remember much except talking, explaining, defending, handing out leaflets. Many politicians passed by us and some had the courtesy to look and read. Some took leaflets inside, so we were getting to them in that way. They could no longer say they did not know who we were and what it was all about. Labor Government politicians were notable by their absence or by walking past quickly, so importantly in their suits and shiny shoes, all paid for by you and me, lest we forget. They have forgotten. Government usually has a short memory, until they return to Opposition.

Andrew Stoner came out and spoke with us, which I appreciated, as did others from the Opposition. But it was the ordinary people who really showed interest. Some of them would begin to walk past quickly but as they passed one poster, two and three they would slow down and begin to read. Don had a remarkably expressive face and a look about him. He was very a handsome man when we met – and for me, always – but it was those eyes which followed you about from the photos. I think that, coupled with the questions on the posters, this meant not many went past unaffected. Some read the life story from beginning to end and many walked away shaking their heads. Just as many came back and asked for the leaflet to take away. Some signed the petition, but it was always going to be that many names were hard won. This was not a simple yes or no, 'Do you agree or disagree.' This one, you had to really read the heading properly, and the information, consider and then decide. For some it was too much to take in. A few said words like, "It couldn't happen in Australia". Some were visibly upset and many of these came and told us about their own nightmare time in the hospital system.

We stayed there until about 3pm. Photos were taken and we felt elated at the end as it had all gone very well. If the then Premier, Morris Iemma, or the then Health Minister, Reba Meagher, had had the courage and dignity to come down and talk with us, the day would have been perfect. I was amused to recall her previous statement made to Parliament: *First, I extend my most sincere condolences to Mrs MacKay. I am sorry that we meet under these circumstances and not outside this Chamber.* Well, Reba here we were: come out and say hello! We knew she was inside. What cowards this bunch of Labor politicians are, and how uncaring and hypocritical. These people seem so far removed from the Labor Party of my father's day that I don't think they deserve the name Labor any longer. They are supposed to care about what happens to ordinary people, and you couldn't get more ordinary than us out the front. Some people say "*Once the Labor Party was the best of the working class but now it is the dregs of the middle class.*"

We were pretty exhausted at the end.

I was aware that the Garling Inquiry was being held at the Sydney hospital on the same day. It was just a fluke. Someone said we should be over there, but I know none of us wanted to go anywhere near that place. That was the day I saw Vanessa Anderson's father coming out of the inquiry on the television news. So I was surprised at Mary Dowling's presence out the front of Parliament. She worked for the Northern Sydney Central Coast Area Health Service (NSCCAHS) and I would have thought that anyone who had been working on complaints at the hospital, as I knew she had been, would have been at that inquiry. She asked me to go inside for a meeting a couple of times but I asked her to wait until we were finished. I may be cynical but I remember once years before when we were getting public attention out the front of Parliament House, when the Greiner Government was trying to privatise our hospital, we were asked inside to meet Mr Greiner, just at a time when we were drawing media attention to our cause. Also Melissa, Veronica and Carmel would have had to carry on if I went in alone, and if I took one of them with me as a witness, which I felt I might need, that left only two out the front which would have lessened our ability to deal with passers-by.

I agreed to meet with them after we finished, across the road in a coffee shop. I was also surprised to also see the CEO of the NSCCAHS, Matthew Daley, attend that meeting, as surely his place was at the hospital and the inquiry? What was so important that both these people needed to meet with me, without appointment and on such an important day for the Sydney hospital? It was quite funny really because by the time we got to the coffee shop it had begun to close down and there was one little round table for all six of us to perch around and it was very noisy. I can't tell you what we talked about, it just seemed to waffle on for too long and then we went our separate ways. I only mention this because it was odd. I had heard a man talking loudly in his mobile phone that morning just after we set up saying words to the effect, "And they've got (the name of the hospital) right along the front of Parliament." He was dressed in a business suit and looked reasonably senior. I wondered was it this call that bought attention to us, or had they just been passing by, perchance? I am sure that Matthew and Mary will have a reason for all of the above, and I am sure it will make as much sense as did that strange, aimless conversation we had with them.

The next part of the petition exercise was the local part. I carried petitions in the car with me and unashamedly thrust them at anyone I even slightly knew. I have reached that delightful part of life where I have ceased to care what most people think about me, apart from Melissa and Alison, some of my sisters and Carmel. I was able to get a really good spot outside the Commonwealth Bank in the main street and also at the local Markets and so set up my stand there, with trestle table, chairs and a dozen sandwich boards. Carmel and Neil relieved me long enough for a pit stop sometimes which I really appreciated, as I wasn't game to leave the stand unattended. Neil was dying from cancer at this time and the memories of him are very clear. Most people were supportive, but I have no doubts a few of those who walked past could have cheerfully spat on me. .

I hadn't considered how awful it would be to sit there, mostly on my own, with Don's face beside me and go over and over the story again and again. Some people

seemed to want to talk for ages, and they were exhausting because it was as if they wanted you to give *them* something or make their day better, but most people were sympathetic. One lady called Denise took away some of the petitions and they came back to my mailbox, all filled in. I was so pleased to have that sort of help. Thank you Denise. There was local TV news coverage; local newspaper coverage and I also ran full page ads in local papers with Don's photo and details about the petition. It cost a lot more than I dreamt it would, but it was worth it because I was telling those people who did the wrong thing by covering up for those who were negligent that not only was I not going away, I was going to be proactive, and I was coming for them in whatever way I could. This fatality was not going to just stay buried, nice and respectable, so they could continue on and maintain the status quo as they expected.

Most days when I got back home and unloaded what was needed, my hands would start their damn shaking and it would take time for this to stop. I mourned my husband, not by sitting in a sunlit garden remembering, which I will do one day; I mourned him by exposing the most personal and precious part of my heart, and allowing that most private thing, my grief, to be public. This is something I would not recommend anyone do unless they feel they are strong enough. I never lost the plot, but there were days when I wondered how on earth I was going to hold it all together. Sometimes I would have to go into town for things and would barely make it back to the van without collapsing in tears, after moments before blithely greeting this or that acquaintance. Although I had daily phone calls from Melissa and Alison and from Veronica and Joan, and the friendship of Carmel, essentially this was a lone battle and I was and am the decider. If I said tomorrow, or at any time in the battle for justice, "Look kids, let's just call it quits," they wouldn't think any the less of me, because they know me and love me. And because they do, they have supported my every action and helped with clues and ideas as to where to or what next.

Andrew Stoner took the petition to Parliament for presentation on 17 June 2008. This day was actually the 39th anniversary of when my father was killed by a drunk driver, so it had a great relevance to our family. Melissa, Chris and I watched it being lodged, then left quickly. It was when the Della Bosca Iguanagate thing was being hashed out, and the behaviour of Premier Iemma on that day was a disgraceful thing for the public gallery to see. Chris had never been in the gallery of Parliament. He got all clobbered up in a suit as a mark of respect, which people should do, I agree. He walked out in disgust.

It wasn't too long after the petition of over 2,000 names was lodged that I realised it was not in Hansard. The Speaker's office didn't even bother to notify me. I contacted Mr. Stoner's office who made enquiries, and were told the wording had not been considered acceptable. Funny that, after launching that petition outside Parliament House with all those politicians going in, after having it published in the paper, no one even mentioned the error until after I had collected all those names. Curious.

Maybe it would have been wiser of them to just accept it, although I was told by Reba Meagher's office that it was impossible, according to the bureaucrats who decide these things. As it was, rather than just slipping under the carpet in

Reba's office, questions were asked in Parliament by Andrew Stoner, and he lodged the following motion in Parliament, on 19 June 2008:

295. Mr STONER to move—

That this House:

1. *Acknowledges a petition addressed to the Premier containing over 2,000 signatures, regarding the preventable death of Mr Donald Mackay of Port Macquarie at the hands of the NSW Health System.*
2. *Condemns the Government's cover-up in relation to Mr Mackay's death.*
3. *Calls on the Premier to respond to the petition by way of writing to Mr Mackay's widow, Mrs Therese Mackay.*

The Labor Government never adequately addressed these questions.

Health Care Complaints Commission

On 22 May 2008, the HCCC Commissioner Kieran Pehm wrote me a long letter; the upshot of which was that basically all the treatment meted out to Don was 'acceptable' and no disciplinary action was to be taken. I have this document before me as I write this; just as I have all documentation I have been sent, should anyone think I am imagining these things.

I responded with the following, which still stands, although they did take me up on my dare and finally examined the X-rays which the Coroner was holding. I am still waiting to hear about that, but going on how much I had to push these people to act, I hold out no hope at all of a positive outcome.

To: Mr Kieran Pehm

Analysis of the HCCC's document dated 22/5/08

Preliminary analysis of the Health Care Complaints Commission's refusal to investigate the death of Donald William Mackay after his surgery and treatment inside the Sydney hospital

We are just starting to look over the letter and attachment sent to me from the Health Care Complaints Commission. Already we have queries and statements which show that Commissioner Kieran Pehm has put his name to documents with flaws in them big enough to drive a truck through.

For us the response of the HCCC verges on the edge of corruption and it appears evident in their so-called investigation that they have more than bent over backwards to ensure that no one is ever to be called to account for my husband's dreadful neglect and lack of care inside the Sydney hospital.

To start with... **almost without exception the HCCC have covered up every instance of neglect in Don's pre-op care and post-op care.** The hospital's internal Inquiry in early January 2008 shows clearly the many areas of inadequacy in Don's hospitalisation. The HCCC seem so hell bent on ensuring that no one from the hospital is accountable and have left no stone unturned in seeking to absolve the hospital and the doctors involved that they have written their response to me in the vein that all was well and nothing was done wrong, which is in direct opposition to the findings of the internal hospital investigation.

We have to, on behalf of the shocking suffering of my husband and our father, ask why they would do this. Who is it the HCCC are working for these days? They have lied directly in their response and fabricated to ensure that they have covered up what happened to Don. Don was a human being who felt pain and suffering and knew exactly what was going on and what they had done to him. After weeks of torture they record him – a dying man – as committing the heinous crime of spitting. In my 35 years with him he never ever acted like this. I have to wonder what was done to him to make him act like this. He may have been trying to get rid

of all the filth they let accumulate in his mouth or he may have tried to spit at them but considering he couldn't even talk past the ventilator, it would have been well nigh impossible for him to spit at anyone. But had he done this I feel it was his last defence against cruelties beyond bearing, as tied down to the bed, gagged by the ventilation tubes, racked by pain, his lungs full of mucus and blood and fluid from their filth, my brave and proud man had finally had enough. What I saw when I was there in the daytime was shocking... and for me they would have been on their best behaviour... what was it that happened to him when I was not there which caused him to act outside of his normal dignity and honour, if that's what actually happened – he had no voice to record his side. He was a most honourable man and it beggars belief to read their reports... My mind wonders what was happening to him at the time... he could not tell me and this still haunts me.

1. Pleurodesis – They have glossed over the fact that the hospital in their internal inquiry admit that the use of ungraded talc is a problem and can lead to Acute Respiratory Distress Syndrome, as happened to Don. They now no longer use this ungraded talc because of Don's death. I would have thought that this would have had some relevance to the HCCC but all they say is "The use of talc for Pleurodesis is common in Australia." The Sydney hospital always had available to them the graded talc they now use (I hope they are still not using ungraded talc) and it is and has been for some time established in the literature that ungraded talc has dangers. Why were they using this product on patients, armed with that knowledge?

2. They say "Time was limited but it appears appropriate assessments were undertaken. Ideally further assessments would have assisted with post-operative rehabilitation."

Why was time limited when Don had travelled down from the local base hospital, "alert and orientated" and totally breathing independently? There was no emergency. The fluid in the pleural lining had built up since before December 2006, It was still, in April, when he went to Sydney, a moderate pleural effusion and it was not recurrent as they like to repeat... it was only a re-accumulation of the some of the fluid which was drawn off in March 2007. There was no history of recurrent effusion. I had had the care of Don in our home without medical help in the months before and nothing happened to him to cause what happened to him in only three days after they went into his lungs without all the pre-op procedures that any Australian cardiothoracic surgeon would have followed. All this is admitted by the hospital in their January Report and directions to avoid a repeat listed in their RCA but the HCCC have said there was no significant departure from the expected standard of care. How can both things be true?

Also the HCCC once again has not done its research properly, stating tests were done on Don at the local hospital on 10 May 2007 – when in fact 10 May was only seven days before Don's death, not the five plus weeks. The document is sloppy and just hashed together. Although the HCCC lauds a list of pre-op assessments done, they go against the Sydney hospital's own internal inquiry which freely admits that there was inadequate pre-op assessment before surgery.

3. The HCCC's expert advised them that there would be no adverse outcome from having the lung of a quadriplegic man suctioned at ten times the pressure for almost 22 hours. Please can someone tell me how this can be true? If there would be no adverse outcome from having the lung suctioned at this measure what is the measure which would cause the Pleurodesis to fail as it did? Bear in mind that the suctioning of the pleural lining was not to remove fluid, as that should have all been removed prior to the Pleurodesis; the suctioning was to suction the pleural lining together like suctioning a plastic bag to stick the walls together so as to ensure the Pleurodesis worked. It failed. Their expert basically told them that suctioning Don's lungs for 22 plus hours would "only" have caused him pain... nothing else. He was a quadriplegic with limited respiratory reserves... and lung injury, as we knew at home from a simple cold to flu could prove fatal... we knew this. Their expert who remains nameless says nothing would have come from suctioning his lungs at 10 times the correct rate. Therefore I have to ask why don't they suction all lungs at 10 times the correct rate and be done with it? Nothing happens. No harm is done. They say that "the failure of staff [these are Cardiothoracic doctors we are talking about] to realise that the pressures were too high is a departure from acceptable standards of care, however given the expert advice there would not appear to be sufficient grounds to warrant disciplinary action to be taken."

So it is fine in NSW to suction a very ill quadriplegic's lungs at 10 times the value recommended... **and being a quadriplegic as mentioned in their report "the pain would be minimal" (see hospital internal report).** This all beggars belief and knowing Don's heightened sensitivity to pain in that area, I therefore question the capabilities of their expert. Do they not comprehend the seriousness of unrelieved pain in any quadriplegic, especially my husband who suffered daily bouts of autonomic Dysreflexia, which meant any unrelieved pain caused his blood pressure to skyrocket? He was hypersensitive to internal organ pain. On this statement alone the HCCC show their shocking ignorance.

What is being said here is that their expert believes Don would not have felt much pain because of quadriplegia. I believe that the Human Rights Commission would be very interested in this declaration by the HCCC. Don had been on opiates (Fentanyl at first and then Physeptone) for years with special provision from the authorities because of the intense levels of pain he suffered. His life was still pain-filled as the medication was unable to cover it. Some days his face would be almost grey with pain. On a rare day he would come out smiling and say "There is no pain right now – it's wonderful"

4. Item "6" on page three is astounding. Titled "Alleged failure to discuss with family the failed Pleurodesis".

They say **"For example in the medical records on 15th May 2007 Mr Mackay was noted as being in 'a stable but critical condition'. The use of words such as these would not be construed to mean that medical staff at this point felt it was not possible for your husband to recover."**

This is a statement that makes me feel sick with the memories. On Monday 14 May 2007 I was called to a so-called conference... not a "family conference"...

just me and them, and told with box of tissues at the ready that Don was dying, and what did I want to do? This was two days before he died! I was relieved, as was Don, because finally he was going to be allowed to die. How can the HCCC state the above in light of this? We were from then on in the hands of Palliative Care... Who does the research for the HCCC?

They say that “there are many notes in the records stating that the family was kept aware of the situation.” While the people writing those notes may say that, this was not the case. Not once were we told that they had suctioned his lungs at 31KPA in Spinal in the first day. Not once were we told that the Pleurodesis had failed and that Don had developed ARDS. I could go on and on here about the things we were not told which we discovered only later in the notes. We were only told what they wanted us to know. We did ask Cardiothoracic a direct question about the Pleurodesis and one of their doctors became quite aggressive with me in avoiding answering. My daughter Melissa and my husband witnessed this. That doctor returned and said he was sorry, which my daughter and Don also witnessed, but still he never told us the truth. But the HCCC is satisfied. Once again I have to defend what I saw and knew and later found out.

5. They also mention here the “multiple extubations” Don was forced to endure. The torture I mentioned to the HCCC was what I witnessed. ICU left him far too long after extubating him. He was allowed to come to the point of respiratory arrest more than once in ICU and they did not act until we the relatives, shocked by his suffering, made noise. He at one time got up to 50 breaths per minute, his tongue going in and out in an obviously painful sort of reptilian manner as he tried to breathe... no one did anything until we erupted as a family and forced them to act. None of this is of course recorded. But physio recorded my concerns; unlike nursing staff physios were always excellent. That’s how the recording of notes is done inside the hospital – it’s up to them what they record and they almost never record their own failures to act. That time he was off the ventilator from 10am till about 5pm and he suffered, he suffered shockingly and the HCCC thinks this is normal practice. My sister Veronica (a renal dialysis nurse of over 25years working in Royal Brisbane) said his treatment was appalling and was sickened by this and she had never seen a patient treated as Don was treated at her hospital. She, along with a family friend and myself, witnessed that day when the nurse ignored his distress till he got up to 50BPM (also unrecorded)

6. In the document marked “Internal Medical Advice”, they say “The critical issue here is that Mr Mackay’s eventual outcome had not been anticipated. Had it been anticipated then most clinicians would not have proceeded with Pleurodesis.”

This is a crucial point. This statement is the crux of the matter. **“With proper pre-op assessment, which they had time for, it is clear that they would not have proceeded with a Pleurodesis”.** They themselves have made this statement. Why did they not anticipate what for Don in his condition would have made the operation more dangerous than for able-bodied people? How could they not anticipate this? So for the admitting specialist to proceed

without adequate pre-op assessment (as admitted in the hospital's internal Inquiry in Jan 08), what does this say about his capabilities? He should have anticipated and thus ensured all care was taken. It was not an emergency. He had travelled on a cold night out of the local hospital to the airport then flown to Sydney, then travelled to the hospital, all without incident. They considered him well enough to give his consent almost upon arrival which is another issue to deal with, but yet the HCCC appears to be trying to drum up some critical time problem.

As to Don's being adequately informed prior to consenting to the surgery – I know, because I was with Don all day on the long day while we waited for the air ambulance to arrive, that he believed, as did I, that he was travelling to the Sydney hospital to have a simple lung drain and biopsies done. That's it.

A Pleurodesis takes some explaining. It also carries the very real risks of failure and when it fails it can be fatal and has been for others. When it fails people can go on to develop Acute Respiratory Distress Syndrome (ARDS) and some people never recover from this. In Don's case this outcome was more likely than for others because of his marginal respiratory reserves due to quadriplegia of 25 years' duration. Don always had a great fear of surgery. There is no way he would have ever consented to that surgery had the risks been explained to him properly. I know that. We know that and that is certainty. It just would not happen. He would have consented to surgery if it was explained to him in a manner which downplayed risks or never even mentioned them. The interviewing specialist cannot recall what he said, but the HCCC say **"No procedures are without risk and this was discussed in the consenting process. In view of this it was reasonable to proceed."**

I was told by the hospital's internal inquiry that the interviewing specialist could not recall what he told Don about the operation. So how can the HCCC be so sure he was warned of the risks? Once again they are bending over backwards to protect the medical profession, regardless of the death of their patient.

My husband would never have gone ahead with any surgery with such risks unless I was there. When he was signed up he was exhausted from the long day awaiting the air ambulance, and debilitated because of his breathing problems. The interviewing specialist signed him, up well before 11pm. He had only arrived on a trolley at the Sydney hospital by 10pm, how could adequate assessment have been done in this time? I know what it takes to get Don into a settled place for the evening; I knew what I was doing when I got Don settled and in a relaxed condition for the night at home and it would usually take about a good hour just to do what needed to be done. **The scenario suggested by the HCCC is impossible. Again I have to query their willingness to constantly defend the doctor and hospital. I thought their role was to INVESTIGATE, not defend.**

The HCCC goes on to say in this section to do with pre-op: "There is no criticism of the surgical work-up prior to Pleurodesis". This flies directly in the face of the internal hospital inquiry which found many instances when the treatment was unacceptable. How can the HCCC then state what they have? Their complacency is odd. The whole document before me is odd and questions need to be asked.

7. Respiratory Assessment prior to surgery

My husband's physiotherapist at the local base hospital wrote on the report which travelled with Don in the discharge papers that "Mr Mackay has a lung age of over 100 years" This was not some throwaway comment as the HCCC says. This was a professional opinion from someone who had worked up the report, based on their knowledge of the capabilities of my husband's lungs. If I were that physiotherapist, I would be very alarmed to see my professionalism downgraded to be "simply comments" as the HCCC states. So the physio's professional opinion holds "no insight into surgical fitness". I think that had they considered this professional opinion the outcome would have been very different. This is shocking indictment on the HCCC's independence and skills at neutral investigation.

Again the HCCC in this section tries to "work up" (for the benefit of those doctors who did and have admitted inadequate pre-op assessment) almost a state of emergency, such that any time wasted would mean Don's life. If it was all such an emergency, his slowly building up "moderate right pleural effusion" which Don and I coped with for months at home while the doctors dithered about locally, where is their proof for this? Waiting one day, allowing time for adequate assessment so that they did not proceed blind into his lungs may have saved his life. Acting conservatively as opposed to aggressively because of the state of his health would have been what a good doctor would have done, a wise doctor, a competent doctor. **Here he was, finally in this majoe Sydney hospital with all the emergency equipment available which we did not have at home, and they could not afford him the duty of care to assess him properly before destroying both his lungs.**

Three days after this dangerous surgery both his lungs collapsed. Please explain how this was allowed to happen, somebody?

The HCCC state that a respiratory physician was consulted later (in ICU) but that it was unlikely surgery would not have gone ahead had this speciality been consulted prior to surgery. Why? After Don's death I spoke with the doctor who is a spinal specialist attached to this hospital and had dealt with Don previously. She had been away and was shocked to hear he had died. She was also shocked to hear he had been given a Pleurodesis and she expressed this to me. She had assumed he was travelling to the Sydney hospital for a simple lung drain and biopsy. She also expressed the thought that for Don, conservative treatment might mean that he may in the future have to have the odd lung drain if the fluid built up again, but that this was acceptable and more designed to keep him comfortable. Don and I and also his spinal specialist knew well that Don would not live for many more years because there were so many problems. We accepted this. We cannot accept what the hospital inflicted on Don and the HCCC should hang their heads in shame. It would have been really good if someone like her from Spinal had become involved when Don was admitted, but as the Nursing Unit Manager from Spinal told me the day of his respiratory arrest and with some attitude, when I queried how he had been allowed to come to arrest after all my warnings – "He was lucky to get a bed in here as he wasn't admitted under Spinal".

It is odd here to see that a Spinal physician was consulted in ICU. From my understanding, although the ICU and cardiothoracic doctors requested Spinal's input on more than one occasion, I was told that Spinal refused to become involved. Who exactly was the Spinal physician and when and what did he/she achieve please?

8. **This next statement from HCCC is bizarre.** They say "Input of either physician in the pre-operative stage would have assisted in the post-operative management, but Mr Mackay's post-operative course would still have been stormy. In view of this there has been no significant departure from the standard of care expected." **"Stormy"...** This is unbelievable. Just unbelievable. The hospital and the HCCC have gone to great lengths to downplay the seriousness of Don's surgery. They sent him out of theatre basically vacuuming his lungs, not suctioning – they hid that when discovered. Instead of then watching him very carefully and taking note of all our concerns which we expressed in the days leading up to the respiratory arrest, they dropped back his observations to six-hourly which is criminal, and they ignored our increasing concerns, yet here they say: "Mr Mackay's post-operative course would still have been stormy."

He would have had better care in a nursing home compared to the negligent lack of care and attention he received in Spinal. So again they contradict themselves. If his post-op was always going to be stormy, why did they not do a proper pre-op assessment and have a duty of care towards my husband Don?

9. **Again they give the hospital the all clear by saying in relation to pre-op assessments, "appropriate assessments were undertaken."** The hospital's own internal inquiry flies totally in the face of this statement. They admit a plethora of problems and their RCA recommended systemic changes be made to avoid what happened to Don reoccurring. Yet the HCCC says **there was no problem and that there "has been no significant departure from the standard of care expected."** Maybe this is the case inside NSW public hospitals and maybe the HCCC is accepting that the standard of care they expect is dangerously low and that whatever happens inside this Sydney hospital is fine because no one will ever do anything about it. Who else can we the patients and relatives turn to if the investigative body has become an apologist for a broken down and dangerously corrupt health system in which no one is safe any longer, much less an old quadriplegic whose use-by date it appears they considered had expired. That's how my husband was treated, exactly that.

10. And to cap it all off, re that dropped suction tube (the culprit who I could not recall because inside this hospital no nurses and doctors had ID badges) **"there has been no significant departure from the standard of care expected."** So because our mouths are not a sterile environment it is fine to reuse the tube without cleaning it, and if one drops to the floor it is not a disciplinary matter to pick it up and put it back in a morbidly ill patient's mouth? That's the acceptable state of health care which the HCCC thinks is appropriate in NSW in 2007 and now 2008?

Don was emotionally a strong man and he cared for and protected us all and we, as much as we were able to, cared for and protected him. But we weren't able to protect him in his last five weeks because of the lies they told us and because of the covering up of mistakes which killed him. His brutalisation and degradation was beyond imagining and still haunts us all. He deserves the justice that a fair, open and full inquiry would bring about.

End of response.

This letter was followed up with the queries from family members, and a supplementary letter which stated:

The Mackay Family query the following –

X-Ray Reports and CT Scans. The family would like to know why the HCCC has not mentioned any of the above 30 X-rays and CT scans which were done first at the local base hospital and then the bulk at the Sydney hospital. It is clear that the reports before surgery done locally (none were done pre-op at the Sydney hospital) and the reports done after differ greatly and even a lay person can read the words “loculated pleural effusion following Pleurodesis” and ARDS, and on and on. They have not mentioned these reports once and they are the clearest evidence that Don's surgery failed badly and then the cardiothoracic team tried to cover up this fact. There is no excuse for this. Why has the HCCC been so sloppy and unprofessional?

They do not query the many bags of blood Don was given, sometimes two in a day although he was not bleeding internally.

The Hospital's Internal Inquiry RCA Report 2/1/08 – the family sees no evidence that the HCCC has inquired of the hospital whether they have put into practice the many areas identified in the hospital's report which the hospital itself admitted were unacceptable. One would have thought that in the guise of investigation they might make it a priority to inquire whether the hospital had actually followed through with these issues, which had they been in practice when Don arrived at the hospital there is every chance he would still be alive today.

Instead the HCCC have just said it was all acceptable and expected care or treatment.

Questions of the HCCC from Melissa:

“RISK OF ARDS IS VERY, VERY LOW CONSULTANT ADVISED” – Did a professional really say this? A lot of research says otherwise if they had looked into it further.

“PATHOLOGY RESULTS & CHEST CT SCAN CONDUCTED AT THE BASE HOSPITAL 10th MAY 2007” – Dad was in the Sydney hospital at this time. It is impossible that these tests were conducted then. Unless they mean they didn't see these results until 10 May 2007, in which case it was too late.

“PHYSIOTHERAPIST NOTES MR MACKAY’S LUNG AGE WAS 100” – This was the physio’s assessment and is valid. They worked on his lungs and understood his condition. They wouldn’t note this if it wasn’t necessary. They were also to be congratulated they were the most professional and caring.

“EXPERT ADVISED THERE WOULD BE NO ADVERSE OUTCOME FROM SUCTION PRESSURE IN TERMS OF RESPIRATORY FUNCTION” – If the Commission must be guided by expert advice, was this person a spinal expert? A cardiothoracic expert? A surgeon? I don’t think one “expert” should have control of this issue; there are too many things to consider.

“FAILURE OF STAFF TO REALISE THE PRESSURE WAS TOO HIGH” – This is totally unacceptable and barbaric. Do they have any systems in place to check or double check this?

“MANY NOTES STATING THAT THE FAMILY WAS KEPT AWARE OF THE SITUATION” – Yes we were taken to many little rooms by various doctors to explain things, but 90% of the time they couldn’t tell us anything & we were left wondering why they had even gathered us. When we did ask specific questions we were bluntly and at times rudely told we were making too much of this or looking too much into this. Funny because nearly all the things we were asking were right on track things they would have known, as we found out later which was too late for Dad.

“MR MACKAY’S RETURN HOME WAS NOT WELL HANDLED” – This is an understatement; it was HUGE chaos.

“RE-USE OF SUCTION TUBE & FLOOR CONTACT WOULD NOT HAVE INCREASED RISK OF MRSA OR INFECTION” – This is crazy! In ICU? This is primitive thinking.

“THE COMMISSION FINDS THAT THERE WILL BE NO DISCIPLINARY ACTION AGAINST THE ADMITTING SPECIALIST” – Why is this?

“MR MACKAY WAS A QUADRAPLEGIC; A PEER ADVISED THAT THE DRAINAGE OF 31 KPA IS UNLIKELY TO HAVE CAUSED MUCH DISCOMFORT” – Are they serious, as a quad he had more organ sensitivity than us. If they had checked with a qualified spinal professional they would find this. This was totally barbaric!! His pain level would have been off the chart. He tried to tell them he had pain but they said it was the drain touching the pleura. Did anyone even check what was causing his pain or was it too much trouble?

The Coroner Alters the Death Certificate

In 2008, the Coroner's office agreed to change the wording of Don's Death Certificate, without a fight, to include his treatment as a cause of death. I felt vindicated. The HCCC said it was all "acceptable", but that was also how they responded to numerous complaints about Dr Reeves, the doctor later labelled "the butcher of Bega".

Following a review by Professor Duflou, Chief Forensic Pathologist, Department of Forensic Medicine, the NSW State Coroner, Ms M Jerram, altered Don's Death Certificate to read the causes of death as being:

- 1a. Respiratory Failure (due to)
- 1b. Recurrent Pleural Effusions and its Treatment
2. Quadriplegia.

The Coroner wrote that 'the reason for the modification to the second line of the Death Certificate is because it is most unlikely that the deceased's rapid, but lengthy, deterioration would have commenced when it did but for the patient undergoing the various transfers and treatment.'

We felt this entirely vindicated the family's view that had Don been treated conservatively, as would be expected with quadriplegia, and had there been a lung specialist locally who would do the lung drainage there; it is likely Don would still be alive today and would never have suffered the way he did.

I still dispute that Don's effusion was 'recurrent', as it was never fully drained or diagnosed, but having his treatment labelled as a cause of his death felt like the first decent win our family had had after such a huge effort. It also helped that the person who decided this was the Chief Forensic Pathologist in the Department of Forensic Medicine for the NSW Coroner's office. I now have an amended Death Certificate that proves it's not just the family being "unreasonable" any more. Now, I could go back to the HCCC and demand they do something – but I could not be bothered. This record of all that happened is more important, and a better use of my time.

Quadriplegia is added in the same way a heart condition, diabetes or any other chronic condition would be added to a death certificate because, Professor Duflou said, 'It is without a doubt a significant condition in relation to the patient's respiratory function and ability to withstand significant physical challenges.'

With the amended certificate and Professor Duflou's reasons for the change, I proceeded to ask the Coroner for a formal inquest, and the HCCC to review their earlier report. The changes to Don's death certificate gave us heart in the struggle to expose what was done to Don and attain some measure of justice for him and the family over his wrongful death. Changing that certificate was the first hurdle; getting anyone in authority to hold a full inquiry was to be the next.

The letter I wrote to the Coroner in early August 2008 elicited an initially favourable response. In that letter, I explained to the Coroner that one of the

main reasons Melissa, Alison and I were seeking an inquest was because “for those of us in NSW there is no avenue for justice”. My letter went on:

We were advised by everybody to go to the Health Care Complaints Commission, which we did in September last year. We provided them with comprehensive evidence of the dreadful and cruel treatment meted out to Don. Don was one of the most vulnerable in our society because of his long term quadriplegia...

The HCCC had to be pushed to investigate. It was a very wearing process taken at a time when I was worn out after Don's extended suffering and death.... The HCCC bent over backwards to make light of these two hospital reports and even fabricated information which would put the hospital in a better light.

The upshot of this is that this body has not learned anything from dealing with doctors and practices like that of the Bega doctor. Don's death is in another area I know, but for those of us in NSW the situation is that there is no investigative body because the HCCC has made it too hard for those of us honestly seeking justice for wrongful death, and hoping thus to prevent the same happening to others.

... It took five long awful weeks of suffering hell for him to finally be allowed to die from the dangerous, unnecessary surgery that was done on him; surgery which was performed on a very debilitated man.... Within hours of their having the care of Don, they effectively killed him and yet their evidence re the HCCC and others is seen as professional and given credence... It appears that as long as they keep denying and sticking together there is little chance anyone can be called to account. They know we will wear out in time and need to take our time to grieve properly.

If my husband had been killed in a car accident, unintentionally and without negligence there would be an inquest. If he had been killed unintentionally and with negligence then the person who did that would have a sentence or fine. If he had been killed by someone who aimed the car at him and drove straight at him relying on him to jump out of the road or for someone else put the brakes on, that's about what I consider my husband's death.

If I had acted towards him as they did and so caused his death, I would be, as his wife and full time carer probably serving a jail sentence right now. I do not comprehend the difference. My negligence would be that of a layperson and the community would be up in arms about this. How much more negligent were their actions?

... I am aware “the coroner's court is restricted to establishing the identity, date, place, manner and cause of death and is not a disciplinary body and holding an inquest purely for the purpose of saying someone did something wrong or provided incorrect treatment is not the function of the Coroner, this is the specific role and function of the HCCC.” I am open to suggestions as to another way to go if not the Coroner's office as at this stage I have wasted weeks writing to the HCCC, pushing them along... then getting more material together, just to have them call what happened to Don “acceptable” treatment.

If not the HCCC, who then in NSW examines, inquires and questions in a fair and open way when something so wrong is done to someone in hospital such that an avoidable death and suffering is allowed to happen, be ignored and covered up? There has to be some body in NSW which can legally investigate these issues. If not, then in NSW a person can be killed in the most brutalised manner, but professionals who would know the risks they were taking and would know not to ignore the warning signs that their risks had caused such dreadful lung damage so

as to end a man's life five awful weeks later are never even bought before any court, nor the victim and family ever receive any justice.

In response, the Coroner's office agreed to review Don's case. Our hopes were really raised – only to be dashed yet again in early March 2009. I was devastated the day a letter arrived from the Coroner's office, informing me that Don's case had been closed, based on a report commissioned from a cardiothoracic specialist.

Reading this man's report, I lost control, for the first time since Don was killed. I sat near the window and started to laugh uncontrollably. This went on for ages and I was exhausted. It was horrible black laughter and when I could laugh no longer I cried uncontrollably for hours. Finally I had the common sense to pour myself a glass of wine and drink it in one go. The crying eased and I felt I could breathe again. I took myself outside in the sun and started working hard in the yard. It was unbelievable that the Coroner's office, which I had developed some trust in, accepted this report. I don't know why, but I felt so betrayed. I wondered if anyone from the NSW Coroner's office had really read and understood it alongside my information.

In his report, he did not answer, nor even attempt to address, the issue of the suctioning mistake, nor did he address any of the questions raised as to why Don was so neglected after the doctors and nurses discovered this mistake. He stated three times in his report that he did not have Don's X-rays and scans, but appears not to have made any requests to the Coroner to obtain them.

He was vague about the draining of Don's right pleural lining locally, and failed to mention that it was a "moderate" effusion at that stage, which was very remiss. He demonstrated no understanding of the sequence of events after Don's surgery, stating at one point for instance that Don had been "extubated in the High Dependency unit", and then sent to Spinal before his first respiratory arrest.

He seemed entirely unaware that in a report sent to me in January 2008 and then forwarded to the Coroner's office, the Sydney hospital had already admitted to a whole raft of mistakes. Accompanying that report was a Root Cause Analysis, so that these mistakes could be corrected inside the hospital. Yet in what was supposed to be a professional, impartial and objective report, their expert made an outrageous comment that could serve no possible purpose other than an attempt to colour the Coroner's view of my soundness of mind.

"Clearly", he wrote, "Mrs. Mackay was absolutely devoted to the care of her husband and understandably so. As a consequence, any deteriorations or communication issues, either perceived or real, would easily have been exaggerated and take on a life of their own."

This statement, in a report such as this, is totally, utterly unacceptable. It negates all the findings of the internal hospital inquiry and Peter Garling's own findings, plus the evidence of myself and our family. Why such a snide, unwarranted, unsubstantiated personal opinion would appear in an official report commissioned by the NSW Coroner has me deeply, deeply concerned. In Volume 2 of his report into Acute Care in NSW Public Hospitals, Mr Garling actually reproduced a photocopy of the illegible notes which caused my husband's lungs to be suctioned at 10 times the correct suction rate for 22 hours.

These notes, and a couple of others just as illegible, were used to show just how dangerous scribbled, handwritten notes in a hospital setting are, with the result that NSW Health has announced it will introduce electronic recording of all medical and nursing notes in all NSW public hospitals.

I did not imagine nor exaggerate what is there in black and white and what is accepted by both the Sydney hospital and Peter Garling. It was this statement which I found so upsetting. The tone of this statement, by someone paid by the NSW taxpayers to be neutral, clearly sought to undermine my credibility, as well the credibility of all the inquiries that had taken place since Don was killed.

I wrote back to the NSW Coroner, Ms M Jerram, making this and many other points, and appealed to her to re-open my husband's case in light of the glaring inadequacies of their expert's report. The answer has just arrived, and this is the upshot:

The report from (their expert cardiothoracic specialist – name removed) was commissioned by the Office of the State Coroner and I am therefore sure Dr intended no offence to you in his report to the State Coroner. The report remains confidential within this office. Her Honour has noted the issues, discrepancies and omissions that you have brought to her attention in the report. However, notwithstanding the personal distress to you, Her Honour is still of the view that under the Coroner's Act, she cannot address those matters and cannot investigate the matter of Donald's death any further.

End of story.

So, I have now exhausted every single investigative avenue within NSW, jumped through all their hoops, and found after two hard, sad and lonely years of struggle that the system is designed solely to deplete your energy, and not to achieve justice and change. Therefore that system must be changed. There is no reason why medically caused deaths should be treated any differently to any other unnatural death in Australia. Yet I was informed by the Coroner's office that even if they did agree to hold an inquest, the findings would go straight back to – the Health Care Complaints Commission.

Back to the very same people whose medical expert declared that my husband would not have suffered any pain when his lungs were being suctioned at ten times the correct rate for 22 hours, because he was a quadriplegic and could therefore feel no significant pain. As Don was hypersensitive to internal organ pain – the very opposite of what their medical expert claimed – this statement alone shows the worth of any medical experts hired by the HCCC. And all roads within the system of medical investigation in NSW lead to the HCCC.

Not only does the system not work, the fact is that there is no system which fairly investigates medical negligence. It is all a construct which appears to work, until you try to get through the maze thrown up by the bureaucrats and politicians which protects hospitals, doctors and medical staff, and actively works against the interests of the people injured and killed inside our medical system.

My Cards Are Thrown; Let Them Land Where They Will

I have had too many kicks in the teeth during my fight for justice, but also a few shining and remarkable shows of kindness, none of which came from the authorities. The medical system and its people all turned their faces away from the shocking suffering inflicted on my lovely Don.

This has been so hard. I never thought anything could be as hard. When people try to commiserate or understand what life must have been like to find yourself, at 28, with two small kids and a severely disabled husband that surprises me. It wasn't easy, but basically, we were fine.

I do not, however, cannot, understand systemic brutalisation, or the weird way so many people are prepared to make excuses for it, or turn a blind eye.

I should not have to be chasing justice on behalf of my dead husband, daughters and myself. Those responsible should be subjected to disciplinary action for the death and suffering of my husband Don Mackay and robbing our daughters of their wonderful Dad. Those most responsible should not be still practising inside the Sydney hospital. It would be better for NSW residents if they were not in the health system at all. How do I feel now as I come near the end of this? I feel empty and hollow, but I feel a righteous anger. This book is my final attempt to expose what was done to Don, and make those responsible answerable.

So now, my lovely man, I gather up the cards, as you would have done, and throw them high in the air behind me, never looking back and 'let the devil take the hindmost'. I will go forward, still grieving terribly but full of hope for our daughters and grandchildren who will carry the spark I held so dear. I have done my best, Don. I have left no stone unturned. I have loved you forever and will always do so, and nothing mankind can inflict can take that away. The late winter sun is going softly down behind those trees you loved to lie out under. There is a chill in the air. It's a gentle time of the year and not long now till the spring comes.

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The undiagnosed pleural effusion.

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Glossary

ARDS – Acute respiratory distress syndrome

Adalat – drug to reduce blood pressure

Ativan – anti-anxiety medication

Autonomic dysreflexia – excessively high blood pressure due to the over-activity of the autonomic nervous system

BP – blood pressure

CT scan – computerised tomography scan (takes X-ray images of the inside of the body)

Candida albicans – thrush; a fungal/yeast infection

Cardiothoracic – branch of medicine concerned with surgical conditions of the heart, lungs and oesophagus

Clonidine – a drug used to treat high blood pressure (hypertension)

Dyspnoea – difficulty in breathing, painful breathing

ECG – electrocardiogram (a test that records the electrical activity of the heart)

Extubate – to remove the (breathing) tube

Golden staph – bacterial infection

HCCC – Health Care Complaints Commission

Haemodynamic – relating to the dynamic regulation of the blood flow in the brain

Hudson Mask – an oxygen mask

Hypoglycaemia – low blood sugar

Hypoxia – condition where body deprived of an adequate oxygen supply

Intravenous drip – putting fluids or medicines into a vein via a tube

Intubate – to place the (breathing) tube into the body

Klebsiella pneumoniae – a bacterial infection

Lasix – medication which removes fluid from the body

MRSA – Methicillin-Resistant Staphylococcus Aureus (also called Golden Staph or the ‘superbug’)

Maxolon – an anti-sickness medicine

Mitral regurgitation – where blood leaks back through the mitral valve in the heart as the valve does not close properly. This increases the pressure in the left atrium and in the blood vessels coming from the lungs

Neurontin – Drug used to relieve pain, pain, especially neuropathic pain

Osteoporosis – a disease where bones become very porous, break easily and heal slowly

Paraplegia – an impairment in motor and/or sensory function of the lower extremities

Pericardial effusion – fluid round the heart

Physeptone – Methadone, indicated for “severe pain of visceral origin”

Pleurodesis – surgical procedure that causes the membranes around the lung to stick together and prevents the build-up of fluid in the space between the membranes

Pleural effusion – fluid around the lungs

Pulmonary – having to do with the lungs

Quadriplegia – paralysis affecting all four limbs, although not necessarily total paralysis or loss of function.

RCA – Root Cause Analysis

Sats – oxygen saturation level in the blood

Sepsis – toxins in the tissue or bloodstream

Spirometry – a test of the air capacity of the lung

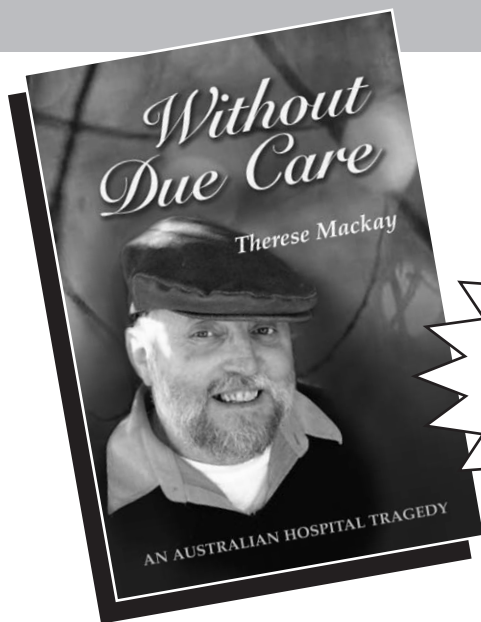
Thoracoscope – a narrow tube with a viewing mirror or camera, used for viewing the chest cavity

Thoracotomy – a cut made in the chest wall

Tracheotomy – surgical procedure on the neck to open a direct airway through an incision in the trachea, or windpipe.

Tramadol – a painkiller

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