Submission

No 14

INQUIRY INTO THE ROYAL NORTH SHORE HOSPITAL

Name: Mrs Therese Mackay

Partially Confidential

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tmackay@tsn.cc
02 65839622

Therese Mackay
"Craggy Island"
43 Willow Crescent
Fernbank Creek
Port Macquarie
NSW 2444
15/7/2007

Rev Fred Nile
RNSH Inquiry
Parliament House
Macquarie Street
Sydney
NSW 2000

Dear Rev. Fred Nile,
I would like to ask you, or ask you to appoint a member of your staff to read through our complaint concerning the way Don was treated prior to his death on 17th May 2007.

I have sent copies of this complaint to Jillian Skinner, Andrew Stoner, The Health Care Complaints Commission, the NSW medical registration Board and the NSW Ombudsman.

I am not inclined at this time to use the legal system to obtain justice for my husband, for his prolonged suffering and his unnecessary death. I would prefer to use those routes available to me at this time as a resident of NSW.

I have complete (as far as I know) documentation of Don's time before Royal North Shore, his short stays in Port Macquarie Base Hospital, X-rays, Ct Scans, Pathology and some notes from Don's GP here Dr

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1. **Document A – From the beginning in late 2006 to Respiratory Arrest at Royal North Shore Spinal Ward 7d 15/4/07 – 30 pages**
2. **Document B – Reasons why Pleurodesis should not have been done on Donald Mackay. - 42 pages**
3. **Document C – Intensive Care at Royal North Shore Hospital from 4am 15th April 2007 till 17th May 2007 – 36 pages**
4. **Document D - 14th May 2007 till 17th May 2007 6 pages**

I make no apology for the personal style which our complaint is written in. I think we have all earned the right to express what we experienced in whatever way seems the right way to us.I had made some notes while in Sydney with Don and gave some of them to the Patient's Advocate which was a pretty hopeless gesture. Those people who have helped me with this are family and friends who visited and saw different incidents and who were all shocked at what had and was happening to Don and around him.

Before I close here I would like to commend those nurses and doctor who chose to treat my husband humanely. Without the relief we all felt when they were on in between the others my husband would have suffered more, if that's possible. I can't identify them as almost without exception none wore identification.

I await your response.
Yours sincerely
Therese Mackay
On behalf of all our family.

TMackay

PS Our daughter Melissa, my sister Veronica a Jackie a friends Neil a Carmel who witnessed many of the incidents are preparing statements which I will forward as they arrive.

Through all of his suffering he bestowed upon us, those who loved him, who he loved, smiles which went on for ages, beatific smiles…diamonds amongst all the shit and dross of the chaos, which is RNSH.

For his suffering which need never have happened, he and our family deserve that at the very least I try to get some justice fro him.

Although his GP said to him in January "And how long do you think you're going to live anyway." something which Don hid from me till he was so ill later on… although the GP thought it was okay to say that with such a lack of compassion, we already knew all of this stuff… but Don's life was sacred and it should have finished when God willed it, when it was to end naturally. Not this grotesque parody played out in his GP's surgery, , operating theatre and the hospital wards he had no choice but to spend his last weeks in.

Someone has to take responsibility, to accept the consequences of their actions. From my recent (this year) experience a man can be mutilated infected and killed, for no reason… but no one takes or expects to take any responsibility at all…ever, and when finally confronted by the perfidy of their actions they become defensive and very hostile, as did Cardio Thoracic in RNSH.

My aims right now

I aim to have Don's death certificate changed to reflect the true cause of his death. The Death certificate signed by 17/5/07 states that the cause of death was,
"1. Respiratory failure three weeks (three weeks??)
2.Recurrent Pleural Effusions - 2 months (Recurrent???)
3. Quadriplegia (He was a Quad for 25 years…why would that kill him?)

(a) Not a one of these is correct.

As evidenced by the many statements by ICU doctors, X rays and CT Scans, Don died as a direct result of acute respiratory Distress Syndrome caused directly from the Pleurodesis performed upon him. This operation was unnecessary and dangerous - he should never have even been considered for this. Why was he?

(b) He did not have "Recurrent Pleural Effusion" of his right lung. He had moderate Pleural effusion in his right lung which was only "part drained" 6/3/07 (850mls out of 1600mls) and all that happened was that it "reaccumulated a month later…not a new effusion…the same one.

© and how exactly did Quadriplegia kill him…he had had Quadriplegia for 25 years?
2. I am also going to move to have my husband's treatment made public and recorded

Document A – From the beginning in late 2006 to Respiratory Arrest at Royal North Shore Spinal Ward 7d 15/4/07

To whom it may concern.

My husband and my daughters', father, Don Mackay should be alive today. He should have been able to go down the aisle when Melissa our eldest daughter was to be married. He tragically died two days before that was set to take place. Of course we had post phoned it when we realised how ill he was. He had a Mackay Kilt ready, a bagpiper lined up to pipe our lovely daughter into the church.

He was alive and looking forward to these expected things. His life was worthwhile and we all loved him dearly, but it was he who projected love into us all. For that we will always be grateful.

This document will be seen by people who mostly are only interested in straight facts. But I can only put those facts into whatever form they come out of me as I write this.

Until I do write this and ensure that as many people as possible read this and act on it, so that not one other person is treated in the same shameful manner Don was, a treatment which was exacerbated by a lack of continuity with his medical care in Port Macquarie; by negligent nursing in the RNSH Spinal Unit; by a hospital which presents as a diseased and dying hospital which was filthy and chaotic but most of all by the unnecessary, dangerous operation done on him, for no good reason which lead directly to his death.

So where do I start and what am I hoping to do? All I know is that when I think on the depth, level and length of my husband's suffering…all unnecessary and know that it was done to him - it didn't just happen it breaks my heart. I know that those eyes which once shone at me and smiled…that mouth which called me "Spider" with such love and humour, will never do so again in my life. This s fills me with such sadness, such a dreadful despair… how do we bear this knowing that it was all caused by an operation which Don should never have had and which he would never survive.

In our minds a crime was committed. The doctor, may feel he did not intend such a crime, but the outcome of his actions feels the same to us. He did not have a duty of care towards my husband, something all doctors should have, first.

When I reflect on the dreadful five and a half week period of dreadful suffering Don had no choice but to endure, again it breaks my heart to consider him bearing the constant assaults carried out on him in the desperate but useless and hopeless attempts to correct the damage done to him by .

so as to have what happened to not him happen to one other person' or to be brushed under the carpet. The doctors who treated him so badly need to know, understand, acknowledge and be held accountable.

The operation done on Don by was not only unnecessary, ill advised and dangerous, but it beggars belief that it was done, even considered at all.

Especially so for a Quadriplegic with limited lung expansion.

should have known this.

3.Then I want to know why on earth he was ever considered for this operation by anyone…the local G.P. , the Lung Doctor from Taree .
Don did not have Lung Cancer, Mesothelioma not any malignancy, virus or bacteria. The cause for the fluid on his lungs was never discovered, even after five and a half weeks in RNSH, most of that spent in ICU.

I want it noted that Pleurodesis should never be done on anyone with fluid on the lung; should never be done at the same time as a biopsy; should never be done on anyone who did not have full lung expansion such as with Quadriplegia.

Dosage is important and normal dosage is 5g not 10 g as was done in Don's operation.

And also that the surgeon blatantly lied when he said one could not have a reaction after 48 hours after the operation, when the product sheet from the company providing the sterile talc in Australia says ARDS CAN OCCUR UP TO 72 HOURS well within the tine of Don's reaction.

4.Also I want to expose the level of neglect Don suffered prior to his first Acute respiratory Distress Syndrome attack. The Nurses notes in ward 7D reflect nothing of what happened the day and before of this event…and the attitude of the NUM I spoke to after the emergency was disgraceful

5. People need to know the state of affairs in ICU at RNSH all of which made Don's suffering worse; the filth, the confusion, the mistakes, the inability to read notes made by doctors and nurses… the whole experience…my sister, a long term Renal Dialysis Nurse from Royal Brisbane, was shocked by the state of RNSH…and described ICU as like being inside an Hieronomymus Bosh painting. When she said this it was as if someone had hit the nail right in the head.

I do not need to prove or show what a truly wonderful, warm-hearted, intelligent, funny (wickedly so), quirky and noble gentleman my husband was. I don't need to prove how very brave he was against the odds - but I will draw in some - of many) dreadful instances of cruelty he was victim of - because he deserves this - and the

sicker and weaker he was the worse the cruelty seemed to be and was.

So I will just start with the earlier letters to Don's "GP" .

There were many things which led to Don's dreadful suffering and death, but what killed him was the Pleurodesis, which he was never going to survive. But before this event and all through the time, there was a lack of continuity of care, and every time there was a chance that a right turn would happen for Don a wrong turn occurred. It was bizarre.

The Beginning.

Late last year (2006, I began to notice a change in how my husband was breathing. 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. He began to slowly become a little more tired than normal.

Here it is important and this will be realised later on why it was so important - any spinal specialist will describe to you that the breathing mechanism of a C5/C6 Quad is so different to the breathing most people experience. When the injury occurs (and I shall provide documentation describing this more professionally than I can) Quads of this level, begin to breathe using the diaphragm. They have much less respiratory reserves than the rest of us. They have ineffectual coughing and vomiting. For doctors dealing with Quadriplegics, this should be well known. should have known this. Don's own GP . I would have thought would have understood this, but as Don was passed down the line of GP's which I will explain at a crucial time in his diagnosis the knowledge of his condition became less, putting him more at risk because of how the notes were written up when he left Port Macquarie for RNSH.

But still the Cardio Thoracic team at RNSH under should have known all of this.

By Christmas the laboured breathing was evident to my sisters Veronica and Joan who visited and also to our two daughters who visited for Christmas.

. has been Don's GP for some years now. He partook when the Spinal Outreach Team, Dr and Dr , came from Sydney and went through all the different issues Don's condition caused. We were pleased with him, that he set aside the time to do this.

As Don's breath became shorter, he found it harder to get his sentences out. His tiredness was such that some mornings when he came out to have breakfast he would go to sleep with the spoon in his hand. I began offering to help him, which had never

happened before in the whole 25 years since Don's accident in 1982.

I was at the surgery the day in January when he spoke to ' ıbout his breathing, but until I get his medical records from . I can not know how this was recorded.

For some reason ' . seemed to fixate on Don's having Sleep Apnoea, which as I slept beside him all the time, I knew full well he didn't. I am a light sleeper. It has me beat why when Don complained of shortness of breath , did not listen to his chest or tap the chest wall...he would have discovered the fluid in January if he had and the outcome may have been quite different.

Don's laboured breathing was always much worse whilst sitting up because of his breathing mechanism. Most of us have an easier breathing if there is fluid by sitting up, but for Don it was the opposite. This is important.

As mentioned, all through this time the build up was very slow, and most of the time he was up and about as normal, but just very tired.

At the January visit, ! . wrote a referral for Don to see a Dr . Dr ` is a Pulmonary specialist who researches Sleep Apnoea, but unknown to us at this time he did not treat people with lung conditions. At this time in the Hastings there is no one who does this. So Don tried to make an appointment with this Dr., he was asked to fax off his medications to Dr office...and then waited, and waited. Finally weeks later we got a response to that referral from Dr saying he couldn't see Don.

On 26th Feb...still untreated... Don went to radiology to have X Ray/ etc because he was booked to have Bladder Surgery 2 days later. It was the radiologist who spotted the fluid pooled in Don's RHS lung. Luckily, because if Don had gone into that surgery with that fluid there his life would have been in danger. I was rightfully very upset with all of this, knowing how Don, because of the fluid and his poor respiratory reserves had struggled.

So I wrote to . hoping to finally get some sort of help for my husband.

"26/2/07

Attn, ,

Since late last year I have noticed Don's increasing tiredness and shortness of breath. Other people have commented on this, as it is a visible thing. Considering Don's heart condition and his restricted breathing due to Quadriplegia this has been a real concern.

Don complained about this at his last visit with you (mid Jan.) and you told Don you didn't think it could be connected with his heart condition.

A friend of ours is a physiotherapist and she said that his breathing should have rung alarm bells with his doctor.

After that visit with you Don faxed in all the material you asked him to send to Dr soon after his visit with you. When he rang last week to find out why Dr had not contacted him he was told by the receptionist that the doctor had not looked at the faxed material yet.

Don then saw Dr R (Urologist) and was booked in to have a Cystoscopy on 28 Feb.

Today while having a pre op ultrasound the Radiographer saw a fair amount of fluid in the right lung.

Since Christmas Don has been unable to breathe properly and unable to see the Heart Specialist till May 5th.

By then...what?

His lungs filling up with fluid would possibly suggest a problem with the heart, as there is no chest infection.

We are disappointed he has been left like this for so long.

Fluid has to be drained from Don's lung to enable him to breathe properly.

Not on May 5th please...

Yours sincerely,

Therese Mackay."

On 27th Feb booked him to have a further X ray and CT Scan which confirmed that he has a "small to moderate right hand side Pleural Effusion".

I woke up Wednesday 28th morning at 4am unable to sleep wondering how to get to someone who would start Don's treatment and so faxed this letter to the heart specialist Dr

"Dear Dr. ,

My husband Don is a patient of yours and saw you for the first time mid 2006. You wanted to see him again in January 2007, but unable to get an appointment till May

2007.

He is a Quadriplegic and has been since 1982. You would have his records but this might save time. He has limited breathing and an inability to cough effectively or to vomit due to Quadriplegia. We have managed to avoid any lung congestion in this whole time and Don has only once had flu, which didn't settle, and it cleared up.
Since about September last year it has become noticeable that Don was having trouble getting his words finished because of constant shortness of breath and was growing increasingly tired. People commented on this because you could see his shoulders having to go up and down…you would know what I mean.
About a month back Don went to his GP but was told it wasn't to do with the heart (?)
Some days are better, but most days Don has trouble finishing breakfast, and is sleeping longer and longer.
When Don had an Ultra sound (Monday) on his kidneys pre a day surgery to look at the bladder, the radiographer saw the bottom of Don's right hand side lung and said, "there's a lot of fluid there"
I suspected this because Don sounded like my mother when her lungs also had fluid build up from heart disease.
So the day surgery is off thank God. For him to have had any surgery with fluid on his already compromised lungs would have been a dreadful risk.
A chest X Ray which I can drop in to you if you request showed up the fluid on the right lung (Don sleeps on his right side…so he can sleep; he can't sleep on his back and too painful for too long on his left).
What is worrying us both is that yet another weekend is coming along and the fluid will continue to build up. Last weekend Don felt too tired and weak to do more than wake up and eat between sleeps but got a little better in the evenings. That was the worst… Monday and Tuesday were a little better.
I realise I am stepping outside the protocol and hope you will understand this.
If I stand back and do nothing, and my husband dies …I can't contemplate this.
Don would most likely not survive any complications of fluid on the lungs such as Pneumonia – he can't cough.

Please when you have time get back to us on this and I ask you respect confidentiality of this fax as Don has a good relationship with his GP. but nothing seems to be moving along.
Yours sincerely,
Therese Mackay"

Dr

He did at least look at the X Rays...and suggest a CT scan...which no one has bothered to look at. Don was so keen to facilitate this that he went along to Dr office with the X ray, hoping that Dr ..... might just look at him physically and see how he was...he did not.

In between this Don's GP had replied promptly to defend his Honour...but did not address the fluid which can cause major problems... honour is important to defend I suppose.

"27/2/07
Dear Don and Therese,
I am sorry you do not feel Don has been treated appropriately. Certainly shortness of breath is a concern and requires investigation. On reviewing the notes from our last consultation I not that most of the discussion centered around fatigue and sleepiness for which I gave him a referral to Dr ...(my comments...Don told me out in the car that he mentioned shortness of breath). We also discussed the bleeding from his bladder and had a long discussion about his dry mouth and medications. Don has complex medical issues and our consultations always cover a multitude of issues. I had certainly not realised that difficulties breathing were a concern of this magnitude based on our recent meetings. (My comment...it was visible and a quick listen with a stethoscope would have found it).

I have looked back through Don's file and Dr letter from last July suggesting he see Don again in 6 months, about now. I provided Don with a referral regarding this in August last year, plenty of time to make an appropriate appointment. I will fax Dr rooms asking if a more urgent one is available but have no final control

over their bookings. This is the same with Dr
...unfortunately I will be away for approximately 4 weeks at some stage in the near future.... (the very next day as it turned out...)"
Dr

Isn't that just wonderful? As Don is not well a fair amount of time is spent at home so I replied ASAP so the would get the letter before his holiday...

"28th Feb 2007
"Dear
We have learned by years of experience that one has to be proactive when it comes to dealing with health problems. We are very sorry if you felt your professionalism as to Don's treatment was being questioned. This was not the case. It was just the telling of an experience by way of providing information which is a good thing.
Don was less than a day from Theatre and apart from the Radiologist spotting the fluid on his lung he would be in there today which could have had a drastic outcome.
A Chest X Ray was done yesterday on Dr R's referral. He would have those results.
Don had seen three Doctors, yourself and the two specialists and all had to observe the manner of his breathing but until Don himself asked the anaethesiatist Dr McLeod after being alerted to the fluid by the radiologist no one listened to his chest. The fluid would have been heard by listening or by percussion. Don's limited breathing at the best of times and his obvious shortness of breath would mean that this is always going to be a problem, without anything else.
Re Don's appointment with Dr. –
Don was asked by Dr to make an appointment with him for late Jan. 2007 but he was specifically asked not to ring to make it till December... then he was given an appointment of May 5th. This was not Don's fault, as he did as he was asked.
Don is just trying to get treated and in his case, he cannot afford to have fluid like this on his lungs and that is the most important thing.
Re DR , we understand we have to wait to get in but he would not have known how urgent it was because he had not looked at the referral and medication list etc we had faxed some time back.
Please don't take offence at this letter, as none is intended. We would like to continue

the good relationship we have with you as you have an understanding of what Don needs and this takes time on both sides to build up. As stated this is intended as only to inform you.
P.S The referral for the CT Scan came through as a blank page last night."
Yours sincerely,
Therese Mackay

We are no closer to getting the fluid drained as its now the weekend we just have to hope we can get things going on Monday...

Around this time Don said to me,
"Do you want to know what my GP said to me at the last visit?" I said yes of course. "It might upset you." I said there's not much anyone can do or say that will upset me these days... Don said" said to me 'And Don just how long do you think (emphasis on think) you're going to live?' "
This comment typified the attitudes we were dealing with more and more.

The CT Scan and Chest X-ray finally 1/3/07 noted, "Right sided (moderate) Pleural Effusion and a small amount of Pericardial Effusion. See Notes and X rays.

In between this time went on his month's leave, the day after telling us and Don was handed over to Dr Young, who did his best and arranged for Don to present via Ambulance (it was the only way into the hospital although not emergency). This happened 6/3/07.

6/3/07 PMBH Hospital
No great problems here but this is important because of what was done. See his Discharge Notes 7/3/07. The Diagnosis noted a Right Pleural Effusion. This Effusion was only partially drained (this is important for later) in Radiology under CT guidance with Dr Briscoe. They took 850ml and left 500mls, because as they were 'quick draining' as opposed to leaving the drain in to slowly drain they were afraid of collapsing Don's lung.

The LMO instructs "For follow up in a month to ensure not **reacumulating. That word is so important. From here on in the Doctors choose another word and called it "Recurrent" Pleural Effusion.** This is where the trouble started What Don had was a rea cumulation as they had never any where near drained his lung. If they had emptied that lung and the fluid had returned that would be Recurrent. The words are important but not so as to abrogate the later surgeon of his responsibility.

There can not be any excuse for the disastrous operation done on Don by
but that word "recurrent" did not help. It appeared to us that they did not understand the difference
Re accumulate - to grow or re form an increasing mass or quantity.
Re Current - happening repeatedly - to occur again. Different from rea cumulate which is what happened with the fluid on Don's lung.

As will be noted on this and the later admission to PMBH and RNSH....
"He was alert and orientated" deviation from this in RNSH was ignored.

The case notes from PMBH on this visit by Dr Stone have mentioned Cardiac failure in notes but unsure of why or what and the connection. I am beginning to think there was a connection from later X ray results.

Dr Grace who is with the Spinal outreach service and who visited Don and I with Dr and Don's GP previously noted 7/3/07 that Don had "low threshold for drainage if effusions present." 98089666. Her input is important as after Don's death I spoke with her and her response to his having a Pleurodesis was frankly one of shock. She thought he was home and well, I shall raise this later.

Dr Briscoe did drainage see CT Thoracic 8/3/07.
Then Dr Young also went on a month's holiday, which along with his own Gp being away left Don in the hands of a Dr Chen, who although well meaning I suppose had not a jot of an idea of Spinal medicine and Don's illnesses.

At sometime in this period, Don's real "last line of defence" Dr (also went away for a long time. She was totally aware of Don's whole condition and his marginal respiratory reserves. Although I say here she was away, because she told me, She was aware of Don's coming to RNSH on 11/4/07 because she was contacted on that day…I do not understand why she did not follow Don's treatment up.

Sadly also Dr Briscoe who could have done further lung drains retired.

This was a tragic set of circumstances for Don as it turned out.

The next month at home was very hard on Don as he struggled as the remaining 500mls of fluid rea cumulated.

Don was mostly unwell, having trouble getting enough air into his lungs. After Dr Young left, in desperation one day we rang the surgery and were directed to Dr Cheng. He came out to the house a couple of times as Don was in bed…it was easier to breathe lying down (this is important for later). He was clearly ill informed of Don's condition. I find it hard to understand how the two senior Docs at the practice could both go away for a prolonged period at the same time.

It was at this time 29/3/07 Dr Cheng finally got a call from Dr Geoff Williams saying he had too many patients to see Don… and also a call from the Spinal people from RNSH who I in desperation had written to and they warned him of the dangers of doing nothing.

We asked Dr Cheng on more than one occasion to arrange CT Scan for Don, but he appeared reluctant. Finally he acquiesced.

PMBH 10/4/05

Don was readmitted to PMBH. We had finally put enough pressure on Dr Cheng to arrange a CT Scan. The result had (who had by now returned) come around to our house on the Thursday before Easter. He wrote us a letter to show to A& E should we need to go in over the long weekend.

That letter contained the first mention to us of the word "Pleurodesis" and the first time that word "Recurrent" was used. What we didn't know was that Dr Cheng had contacted a Dr Peter Baume from Taree (Pulmonary Specialist) and he mentioned Pleurodesis…but that without seeing Don, which is a worry.

I did not understand the significance of all of this at the time and I know Don didn't either. How could we? We were flat out just living. That "understanding" should have come from the doctors who should have understood or made it their business to understand what a Pleurodesis would do to Don.

Although at this time Don was tired a lot…it was not an emergency…but it needed treatment. The day before he went to PMBH we went into town. He went to the TAB and amazingly won $600 and had a haircut… we had lunch in town. Nice memories.

The day he went to PMBH he went up the acre long path to our home. I asked him did he want company and he said which was unusual for him, as we used to hook the garbage can on the back of his wheelchair and take the garbage out that way…he said "No thanks…I just feel like doing this myself." It breaks my heart over and over to remember seeing him there right out the front of our place, looking back. I was concerned about him, and observed him from time to time. He stayed there for ever so long just looking back. I can only imagine his thoughts.

He was terrified of going back to RNSH and swore he never would. He said to me many times he probably would not survive if he did. Every time he went there he ended up with MRSA, in isolation and needing to be there much longer than expected.

He had also raised the issue months before that should he ever be so ill as to need to go on a ventilator he wanted me to make sure that did not happen. It was almost frighteningly prophetic.

Results of 2/4/07 CT Chest "Moderate right Pleural effusion" No mention of

Recurrent PE in PMBH's notes.

CT 10/4/07 Moderate Right Pleural Effusion - size unchanged since 2/4/07. No Pneumothorax, no mass etc. Decision made to admit Don under Cardiothoracic.

11/4/07 PMBH Dr : noted that don was more comfortable lying down…breathing easier. Cardiothoracic in RNSH seemed unaware of this peculiarity of Quad respiration.

Don was then accepted by the cardio Thoracic team at RNSH for transfer…

Don's admitting specialist was - Cardio Thoracic Specialist

Transfer to RNSH 11/4/07. It has to be understood that on the day Don was to travel to Sydney by Air Ambulance…it was not an emergency. It was the only way he could comfortably travel because of his severe Osteoporosis and other conditions. Long car travel was impossible. This needs to be understood. It is important later to realise this. What is also important to understand is that on the day he went down, he had been at PMBH all day, awaiting news of the transfer. He was already very tired the time they came to take him to the airport. He left PMBH at 8pm at nighttime. For a Quad to be transferred like this was quite an ordeal as once he is out of his wheelchair his nursing needs intensify.

The discharge notes by VMO Dr call it a "recurrent Right Pleural Effusion but in his later notes he calls it a rea cumulation…see PMBH Notes.

As it was as they were lifting him from his bed to the trolley, a large wart he'd had on his chest was ripped off and bled onto his T Shirt. I pointed out the spreading bloodstain to the nurses and lifter but this was not noted. Don had full feeling there. By this time we just wanted to get it over with. We were both worn down by the long process of just getting to this point.

I travelled out to the airport with Don, ensured the Ambulance Nurse had his Adalat

close by for his Autonomic Dysreflexia. I said goodbye and arrive home at about 8.30pm The next time I would see my husband he would have already had the Pleurodesis, and unknown to both of us, he had at that point no real chance of survival. I drove down to RNSH early the next day and after parking across the road at the Greenwich Inn and unloading Don's chair etc and all his gear which couldn't be taken on the plane, I arrived in his ward at about 1.30-2pm.

Back to Don's admission RNSH . Don was admitted to Ward 7D Spinal at 21.45pm. Knowing what it would take to unload him and make him comfortable in bed, administer all his medication it is beyond me the next sequence of events…how it could have all happened in the next hour. By 10.45 a says in Don's notes "For right sided VATS (Video assisted Thoracoscopy) Pleural drain and **Pleurodesis. I suppose the Biopsies are implied here** although I see no mention of them in these notes but they are on the consent form which says "Right sided Video Assisted thoracoscopic pleural biopsy, chest drain, pleurodesis and thoracotomy".

It was noted his skin was in good condition.

Now here is the thing I would like to know… I see that Don has signed this consent form, within the hour… I assume he would have either been in bed or still on the trolley; I would like to know exactly how the Pleurodesis was explained to him… in what words was he told of what this operation could mean to him; and how in that position was he able to read the whole consent form. Someone would have had to find his glasses, and stand there holding that form very still or else stand there and read out every word. Somehow I doubt that this would have happened. How on earth would he have been given and had time to absorb all the possible side effects of Pleurodesis and then make a fully informed decision.

Whether or not he understood the true risks to him is beside the point. A Quadriplegic, with limited respiratory reserves, a lung with fluid in it, unable to fully expand his lungs; having biopsies and given the max dose of talc should never have had that operation… was never going to survive it.

The simple thing is that operation should never have been done on a man in his condition. and this should know this, but I doubt Don was properly examined re his respiratory reserves. There just was no the time.

10.45om one hour after arriving at RNSH the Operating Theatre was booked, the die was cast. All we thought he was going down to RNSH for was for them to put in a simple lung drain and leave it there till all the fluid slowly drained away, to do biopsies...and then to send him home if the biopsies were okay. We had never heard of Pleurodesis - in common with most people.

Dr (Spinal) said exactly the above to me when I spoke with her after Don died.

The haste was bizarre. All of this needs to be examined. There was NO emergency.

12/4/07 RNSH

I had as mentioned travelled out to Port Macquarie Airport to see Don off on the Air Ambulance. At 8pm he was in reasonable spirits. It was quite cold and I made sure he was warm, made sure he had his beanie on (his head was often cold) ... I remember as he was wheeled to the plane, he lifted his head up a bit and smiled at me and said "See you tomorrow, Spider." (A nickname). Mine back was as always "see you round like a rissole... and he called back the proper response "Eh! EH!" (we were long time Aunty Jack fans) Spider was a term of endearment for me...don't know where it came from. It just was. I liked it because of how he said it.

That was the last time I was to see Don when he had any real hope of survival... and it is hard to bear.

When I arrived in Sydney at 2pm the next day (12th) the operation was over and he was sitting up in bed smiling – his big surprise for me was that it was all over, all done...and no doubt we'd be home next weekend. He was cheerful and happy that day, and fully recovered from the anaesthetic.

I and he most likely had no idea what had been done on him in theatre. There was some vague talk of Talcum powder and the (I think) seemed very pleased with himself. I suppose when you tell laypeople about putting talc into pleural linings and watch eyes widen in disbelief it might feel good…but he never once mentioned reaction at this time.

Near the end of this day I noticed slight things which concerned me about my husband. Just the odd thing he said which seemed out of place. Not much. It had been a torrid time and I was as exhausted as he must have been. 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.

From RNSH NOTES

12/4/07 00.300 am a (can't read these notes well unsure of his spelling)

The notes keep mentioning that Don was transferred for "pleural drain, biopsy, VATS – Pleurodesis" but before leaving port Macquarie Don and I had heard no mention of Pleurodesis at all not that it would have meant anything if we had. But once those words "recurrent" and "Pleurodesis" got into the notes they had a life of their own and he was as good as dead, because with his extremely limited respiratory reserves due to his Quadriplegia he was as likely to survive the Pleurodesis as if he had driven at high speed on a wet road, minus seat belt into a brick wall.

It was that certain. Nothing researched, tells us anything different.

We feel it was really bad medicine.

This , states, "previously admitted with **recurrent pleural effusion" and so the myth grows.**

He was only admitted to PMBH 6/3/07 with "moderate effusion" which rea cumulated as it had not been fully drained…then readmitted to PMBH 10/4/07 only one day before they signed up my poor tired husband to have a Pleurodesis. No way on God's earth would he have risked his life to have that operation had he realised the risks of ARDS… which is what killed him. I will provide the many reasons why this

operation was unnecessary//dangerous/ fatal to him later in these notes.

This doctor even had the month that Don had the effusion tapped wrong (one of many record mistakes). He says 4/07 (April) it was 3/07 March and had rea cumulated.

The nursing notes here are of interest because even after the long day he had had on 12/4/07 she notes he was "alert and orientated". **Any later deviation from this should have rung loud alarm bells!**

The nurse queried Don's MRSA positive status (tagged), as he had not had MRSA in PMBH. But using the old 1980 notes from RNSH he had had MRSA… He was clear of MRSA at this time and the records show this.

He returned to the ward at 12.30 - 12/4/07 after the operations, the next notes from nursing staff are at 15.25pm. A long time between observations, unless I don't have all the notes and obs were made somewhere. The times between nursing notes in Spinal were stunning.

(They have him taking tramadol…why is this?)

The notes mention his right (not shoulder) but upper arm pain. That arm remained painful after the operation and misshapen…the girls (Don's adult daughters) noticed this "lump" from the time of the OP till when he died. This like many things was never fully looked into. I have taken care of my husband since 1982 and I know every inch, every lump and bump…something had occurred…which caused him pain. Running your fingers over the top outside of his arm you could feel a hard bump as hard as bone… was told it was nothing but referred pain. Something quite drastic happened to that arm, possibly wrenched above his head for the op…it had been years since it had been able to range properly. This I guess is not that important, just indicative of the lack of concern and care in Spinal.

The notes from Spinal Nursing are a joke. One set made at 16.40 the next at 4am the next day. This is ridiculous for any hospital ward much less a Spinal Unit.

From her on in till his Respiratory Arrest the nursing notes differ greatly from my own. If you just went by what they have written of the time before the event no alarm bells would ring but the reality was that a level of cruelty was imposed on my poor husband, which increased, the more seriously ill he became. I will never forgive these nurses for this.

Melissa (eldest) came in to see her father on Friday 13th April. They had a nice visit and the beginning of the day was not too bad. He 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. I knew the signs from home of how that looked.

More than once I drew the nursing staff's attention to this but was just told over and over that his "SATS are okay" (O2 Saturation). This parroting "SATS okay" 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 (diagphram) to allow more breath in…this is how Quads breathe.

They looked at the instruments and ignored what was happening. Nowhere in their notes on 13th and 14th have they noticed my increasing concerns and queries and panic at later stages.

Saturday 14/4/07

Dr Can't read notes… mentions that at 5.30am there was agitation and Don's SATS were down. He says that his impression was that the agitation was hypoxia and to maintain a Hudson Mask.
(After a pleurodesis alarm bells should have rung loudly NOW)

Then the Cardiothoracic Dr., recommends and okays a nasal prong O2 delivery system…I cannot understand this WHY? Don was visibly mouth breathing! And then she recommends him sitting up! (this always made Don's breathing harder and worse…Cardiothoracic did not seem to comprehend the breathing mechanics of Quadriplegics and show this by this order)

You and I sit up if we have fluid on the lungs and this makes it easier…but for Don is was the opposite. His diaphram had to lift up the chest wall and open the spaces allowing his lungs to expand… a layman's explanation from 25 years observation… this was hard work but more so when sitting up.

14/4/07 Nursing notes are illegible as are much of Spinal and ICU notes. God knows how anyone knows what happened two days before.

Don asked for the Mask as opposed to the Nasal Prongs. He knew by now he was in trouble, but not why…and this is Dr and his staff's fault.

His SATS should have been maintained at 95.1% and above but dropped to 89%. The nurse noted (see notes) "patient (who upon admission was alert remember… my comment) muttering to self and disorientated to place and person…. reorientated" (oh really)
Now one would think they would get worried. No.

Dr (Cardiothoracic) "unconcerned –he is post operative"

This is a shocking thing. He came out of the OP and was smiling soon after, clear headed and aware and here we are 2 days later after a Pleurodesis known to cause Acute respiratory Distress Syndrome of which Don had all the marker of and she is "unconcerned".

Poor Don, he trusted them! I didn't but didn't know what was happening. No one seemed to have a duty of care for him. He was beginning to be treated as if he was a damn nuisance.

Again Dr says she wants him out of bed upright (in his wheelchair) and to go to 6 hourly nursing OBS (I thought they had already done that…unless I don't have all the notes.

The nursing notes after this in Spinal Ward 7D are a disgrace.
14/4/07 12.25hrs – read them. … next lot at 22.00pm. Unbelievable.
They record nothing of what was going on. They are noticeable because of the absence. I had trouble finding any nurses on this horrible Saturday and went from ward to ward over and over because my husband was so distressed. This sort of neglect for a C5/C6 Quadriplegic of 25 years who has just had his lungs interfered with in surgery...always a major concern for any Quad

Respiratory Arrest No. 1

And here we go… my lovely husband is well on the way to Respiratory Arrest and consequent death five plus weeks later…leaving us all. This man had suffered unbelievable pain and indignity over the past 25 years but this was nothing compared to the horror that was about to unleash itself upon him, and because we love him, on us also.

I feel I will never recover from what I know and what I saw in the following weeks, my poor gentle man endure in that diseased cess pit of a hospital called RNSH. I hope our two children do and my sister who was there. I am hoping to get justice for my husband and by this free our family because it feels like we are daily re living a horror which was preventable and which was done on him.

On Saturday 14th I arrived at 10.30am. He appeared a little disorientated. I was not told by nursing staff or doctors of his overnight agitation or SATs drop. He was saying a few things a little out of character and becoming increasingly agitated. This unknown to me was the side effects of CO_2 building up in his system pre 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?

(after Don's respiratory Arrest on the next morning, Dr   told me he had been to visit Don at 10am on Saturday 14th, half an hour before I did and that he was fine…I have found no record of that visit in Don's notes. Don was most certainly not fine))

I began mentioning this to the Nurses. To Don's nurse, to the NUM, to any nurse I could find, as ours seemed to be not there all that much. I also mentioned the by now visible thing of his shoulders and chest moving up and down, trying to breathe, more laboured as the day went on.

Not one of my many concerns is noted not once on this day, I find this lack appalling. I really thought that they may have been noting my very real and spot on observations and concerns. They did not even bother to make one note.

Alison our youngest rang me on my mobile that morning after speaking with her Dad on the phone at 11am. She was very concerned because he was not really making sense on the phone and also had forgotten that his eldest Melissa had visited the day before. This was very unusual as our daughters are adults and live away from home so when he saw Melissa the day before he was over the moon and we took a little mobile phone snapshot for the occasion.

I told the nurses this. I told them he was having increasing difficulty breathing and that his shoulders were going up and down faster. Not noted. Not even mentioned.

At 1.30pm under Dr "orders" he was lifted and sat up in his wheelchair. Straight away his breathing became more laboured in this position and at times he appeared to be a waking sort of a dream, making strange connections...for example the man Norman in the opposite bed was reading a book with the author's name on the back. Don fixated on that name and said that that was the name of his doctor. But then he flipped back to being totally lucid and frightened. He knew things were wrong but we did not know what.

He got me to set him up with his toothbrush so he could clean his teeth. Then a little while he asked me to do it again. Which I did. Then again about half a dozen times at least he asked to have his teeth done.

A little while into sitting up he asked the nurse could he go back to bed, because he was feeling nauseous and having trouble breathing.

She told him to wait till 3.30pm when the Lift Round came again, and seemed oblivious of his obvious suffering. I offered to try and help get him back into bed, but that wasn't allowed. It seemed that no amount of being sick made this nurse deviate from whatever plan she was running to, certainly not an ill patient.

The lift round came at 4.30pm. His breathing greatly eased as he laid back in bed exhausted, but he was worse than when he went into the chair.

Because he was becoming increasingly dangerously ill, the build up of CO2 in his system was making him very agitated and he was breathing fast. He did not seem to be having his breaths per minute monitored and considering Dr ! had him on 6 hourly Obs, he was not monitored well at all. Nursing staff seemed unaware that the man they were dealing with was totally unlike the one who arrived on the ward at 9.45pm 11/4/07 who was alert and orientated.

I cannot understand this. I am not a nurse but anyone could see something was happening. He just wasn't making sense most of the time and then he would…that would make them happy and off they'd go "SATs Okay!" A nurse came around about 6.30pm at my insistence and asked Don very loudly who the Prime Minister was and his birth date (Don's) etc all of which he answered correctly, and off she went, seconds later he was seeing things in the corner of the room and talking away about nothing.

I started for home at 7pm totally exhausted, emotionally and physically. I only wish I had stayed, but I had no idea this would develop to an emergency, I just knew something was wrong. I wanted to be back there early the next day to catch the doctor and try and get some decent care for my husband. I was frightened for him and I knew he was frightened. I spoke to the man Norman opposite Don 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 nurses attention and they did not stick their heads in very often, especially not to Don, who he knew and I knew had become a "nuisance"…they get "blanked" I had no one I could ask to come and

sit with him all night which is what should have happened. The previous weeks had been awful for us both and I felt I had nothing left and needed to sleep.

I left and still remember walking down the hill to the Greenwich Inn (Rotary) shocked to my core at what had gone on. I can not remember how many times I went to those nurses sick with worry…"SATs okay" was all I ever got. Again as mentioned it was unbelievable that not one nurse had noted my many concerns.

He knew how they were treating him and he knew he was in trouble, as did I. We just had no idea how bad.

Before I left I told his nurse that if at any time during the evening and night he called or needed me, to ring me that I was just 5mins 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 she didn't have my mobile or where I was staying and that they had no "Next of Kin" written in.

Yet I found all that information in the admission and discharge notes from Port Macquarie Base Hospital. I had also given this information in when I went to Admission. So if I hadn't thought to actually ask to be notified they would have had no numbers to contact me on.

The notes after I left that day are self-evident and raise many questions.

I was told by the man Norman (from Ferguson Lodge) who was in the bed opposite Don, when I went to collect Don's things from Ward 7D that Don had called for me by name for about 2 or three hours the night before his Respiratory Arrest. The nursing staff did not phone me once on either number. Don would have hoped I was coming. For a man so ill to be treated like this was cruel in the extreme. It distresses me to know of this and they should have rung me the first time he called for me and also when he was becoming dangerously ill. THEY DID NOT. He must have been so frightened. He called and called and called and TRUSTED I would come, would

always be there as I said I would. But those bastards never called.

I wonder did he think that they had phoned me and I hadn't come? I was only 5 mins away, and asleep till finally I was called by the Intensive care Unit after 4am.

The reason I was up in ward 7d and spoke with Norman, was that all of Dons things were just left strewn all over his side of the ward and bed. I had realised in ICU that he didn't have an Air mattress under him, which for a Quad was needed. I had assumed he had one of theirs or that they had delivered Don's, which had been on his bed in 7D. So when I arrived in 7D I was disgusted to see how they had left all his things. His $2,000 air mattress, lucky to still be there and this took me about 30mins to disassemble; I had to find his electric wheelchair and pack up his locker and cupboard and get it into some form of order so I could manage to take it to him.

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 Ward 7D came near me. I could not have been more invisible. They turned away, the one or two I recognised. No one queried did I need help, nor had anything to say to me at all. No help was offered to help me get his quite considerable amount of stuff downstairs to ICU. There was too much for me to handle and take and I did not want to leave it, as things go walking… it had all cost us many thousands of dollars and was needed.

Finally I rang ICU and they sent down one of their wards men.

I felt angry, sick and humiliated at having to scrabble about like this at such a terrible time.

Respiratory Arrest.

How did my husband have a Respiratory Arrest? How was it let to get to this stage? Despite all of my warnings, despite this being a Spinal Unit and with the knowledge they should have had how was this first arrest allowed to happen to him?

In a Spinal Unit?

Don had been a Quad for 25 years. The Spinal Unit and Nurses would have known that just about the most serious life threatening thing which can happen is anything which compromises the lungs. They left his "set up" by orders of Dr with O2 Nose prongs after I had told them more than once that he was mouth breathing and somehow they didn't take seriously the fact that as he was breathing, on the out breath his tongue started to go out and in on the in breath. This was really odd. His breathing was fast than it should be and he was distressed. All signs of imminent respiratory Arrest as I learnt when we went to ICU...I saw this exact thing happen to him about 4/5 more times when they tried to Extubate him.

I had never in my life seen anyone breathing like this. I showed them over and over. None, not one of my concerns noted.

The attitude of the nurses which developed towards Don was reproachable. It wasn't about how busy they were, as they were quite pleasant and patient with Norman. But because of the effects of the build up of CO2 in Don, and his agitation and my constantly trying to warn them, we were obviously annoying them and as mentioned before "Blanked"...many people with Chronic illness know about this "blanking". It was only when I made them come in. In a hospital, a Spinal unit their casualness was negligence.

When I became concerned on Friday afternoon and increasingly alarmed on the Saturday 14th April, the very fact that I have lived with this man for 35 years since 1972, and for 25 years as a Quad since his 1982 accident and that I have been his wife and with him seven days a week almost 24 hours a day, commonsense should have dictated that nursing and doctors should take seriously my concerns. My observations were relevant, accurate. Their sparse observations were perfunctory, and careless.

Don was becoming less lucid and so frightened and having increasing trouble breathing all of which was visible and audible. How could they not see this? Why did they not act? Are they that badly trained? But when I look at their sparse and sloppy notes all though they kept telling me his "SAT's" were okay, even that was a lie.

They were not okay. They were up and down all the time – why did they not take into account his increasing delirium might be caused by increasing CO2 as evidenced by his strange breathing…all of this is well known medically…what was happening to him was text Book reaction to a failed Pleurodesis.

Instead when they bothered at all they "placated" him and may they rot, he knew exactly what they were doing. He was a very intuitive man and not much slipped past him, he was used to these sorts of "subtleties" even as ill as he was.

What was wrong with them? What was wrong with Dr .? Dr would have known what was happening. Once ARDS happens after Pleurodesis, in Don's case Death was likely. I think Cardio Thoracic knew too well.

There is no doubt at all that the unnecessary, dangerous, failed Pleurodesis caused the ARDS which killed him finally, but had Cardio Thoracic and Spinal been more professional, maybe things may have been turned around at this point, although I doubt it.

When I was sitting next to him in ICU after his respiratory Arrest and the Dr just mentioned if he progressed he would be going back to Spinal, as doped up as they had him and with all the tubes in everywhere he thrashed his head from side to side. He was terrified. Terrified. I don't know what happened after I went that night but his reaction was of great concern to me. Don had for years suffered much pain and indignity and he was a brave man. This reaction was unlike anything I had ever experienced with him. It was terror.

I hope Norman the man in the bed opposite Don who came from Ferguson Lodge can give some input on what happened, if he is still alive.

In Spinal, the nurses and Cardiothoracic made "judgements". They were wrong and why all of them were so wrong has me asking questions. It was plain to see how ill he was.

The Observations prior to Respiratory Arrest.

I urge you to look closely at the observations made in Spinal and the distance between them…

On 14/4/07 the last recorded notes of the nurse whose name I can't read, as with most was 22.00. Then not one handwritten note till 7.50am the next morning and then it was all in retrospect, written so as to fill in all the time in between. If there are any decent Obs taken then please someone point them out to me. I can't find them.

Also when Dr came in 13/4/07 the day before, no time is given…even within an hour would do. The notes in Spinal are threadbare and sparse to what I feel is a negligent level. Not good enough for very ill people.

On 14/4/07 Dr does put in the time but below nursing has scribbled over the time.

Then 15/4/07 obviously very early Dr (Night Intern) begins along with others 3 pages of notes. No times are mentioned at all. No mention of his calling out for me by anyone. Why would they? And in all those hours they would have had time to phone me.

Most is illegible and they will need to translate so that any sense at all can be made of it. How on earth anyone coming along days later could understand what happened beggars belief.

Later after the Respiratory Arrest I spoke to the Spinal Nursing Unit Manager (NUM) about how frightened Don was of coming back to spinal and that if he were sent back up would he be looked after…instead of understanding my fear after what had happened to him, she quite tartly said,

"He didn't have to come to spinal in the first place because we were doing him a favour by taking him as he was admitted as a Thoracic patient."

Blame the patient again. No compassion, no acceptance of any problems in Spinal. I had been urged by the "Patient's Advocate" Nick Rich to meet with this NUM, and I

wish I hadn't wasted my time and caused myself even more stress. It was a useless exercise. He was Spinal whether or not admitted by Spinal. He was Spinal because he was a Quadriplegic and one place in the whole hospital which should have understood his needs was Spinal. They treated him like a nuisance.

And so back to the lack of Observations. It would be easier at times if you are reading this to have the hospital notes alongside if you need to check points. Much of these notes I cannot read, nor translate from both their shorthand, and also their illegibility. Someone else will be needed to do this.

On 14/4/07 at 22.00 the last of the nursing notes before this were made at 12.15pm. I can't find temperature, BP and other observations in all this time and he was very distressed on this afternoon as mentioned. They may exist but I can't see them here, and did request ALL the notes.

I have since discovered that the Acute respiratory Distress Syndrome which was what Don developed from the Pleurodesis can happen up to 72 hours post op. Dr said it would only happen in the first 24-48 hours. He is wrong. I got this information from the product sheet of the Australian suppliers of the Sterile Talc used.

1/4/07 Back to Dr No time mentioned again…he noticed 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.

<u>2 MAJOR INDICATIONS OF DEVELOPING ARDS – CONSIDERING PLEURODESIS!</u> What on earth was wrong with these people to move so slowly?

Then he adds "Nil signs of respiratory distress" and "SATs back to 95%"

What time Dr and when was this…an hour before the 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 a fool could see was

happening.

15/4/07 Then someone called – unsure who this is…this person visits – (no time given) and notices "SATs down and agitation and ATSP" whatever that is.

Whatever happened this night to my poor husband? At some point just after the Respiratory Arrest it is mentioned that Dr has declared "Talc Pleurodesis Reaction unlikely."

A rather quick diagnosis without any testing. But as the person who did the Pleurodesis he would be inclined to say this considering what all the ICU doctors added in the dreadful weeks following this. Even one of his own team stated this later on. Why would he make this statement at this early time?

15/4/07

In ICU. Can't read first notes. They have the wrong dates and cause of Don's initial accident. Instead of his being a 1982 Diving accident it now becomes a 1988 Driving accident. Even in sorrow, you have to laugh.

These notes now by Dr and I cannot read and will ask that they be translated. But the good Dr notes at 7am "Respiratory Failure and Inflammatory Markers? Talc reaction"

Then there is the record of the Medical Emergency event which is there and legible. His Respiratory Arrest was at exactly 3.51am. I have watched Don come exceedingly close to another arrest in ICU after he was extubated and my sister and I watched in horror as his breaths per minute got up to 50BPM!!! His tongue was going in and out of his mouth so far that it would have been painful (and the nurse at first told us he was trying to talk behind his mask…but that's another incident) Luckily this time we got their attention. But he was intubated before the respiratory Arrest.

What in God's name was he like in Spinal to get to that stage and how was this allowed to happen? Someone has got to be accountable for this as well as the Doctor who did the Pleurodesis and left him so badly monitored. I think 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 those nursing notes all written in one hunk at 7.50am 15/4/07 that don had desaturated to 83%. Again the nurse has not mentioned the time at all.

I find that along with all the other things this sort of notation is fraught with danger. Time is all important.
The next part from 15/4/07 to when Don died late on 17/5/07 was all in ICU and no matter what happened there, no matter his dreadfully cruel suffering not one minute of it needed to happen because as the Intensive Care Specialist Dr Anthony Delaney stated 22/4/07

"Mr Mackay has deteriorated post extubation today. Again he has developed delirium and hypecubic respiratory failure.
The cause of his illness is not clear to me; I suspect his Quadriplegia has left him with marginal respiratory reserve that has rendered him incapable of ventilating after his pleurodesis.
His CO2 has gone + + (next bit illegible) I have reintubated him."

I will treat the time spent in ICU from here on in, in Document C but first in Document B I will lay out with references the many reasons Don would never be suitable for Pleurodesis and would never survive one.

As an add on – today I finally received from RNSH Mecical records a copy of my husband's observation chart from the 3and a half days he spent in Spinal 7D. I had noticed that even though I had asked for all the notes they had not sent al. There were no observation charts for Spinal and ICU.

I rang them about 3 times and finally they responded and posted me one sheet of A4 paper. These are all the observations taken from about 11pm on 11/5/07 till about 4am on 15/4/07. They are a joke and do not reflect what was happeneing but clearly show he was not being cared for adequately and safely. I would never at home, without his being ill, leave him for that long without making checks, and all I had

was a hospital of one, 24 hours seven days a week for 25 years. I would have been negligient if I had left him like they did, and I am just a housewife.

RNSH needs to address this asap.

Document B – Reasons why Pleurodesis should not have been done On Donald Mackay.

Don was a Quadriplegic of 25 years duration . He was a non-smoker for 20 years and then had only about 5 a day before that. He had only had one lung infection in 25 years.

He was given a Pleurodesis with only minutes to take in what it might mean to him. I seriously doubt he was told of the real risks to his life.

His Pleurodesis was done at top dose of 10g. . although this is changed later in typed notes to 7g. ?

It was done while he still had fluid on the lung treated.

It was done after biopsies were performed.

He has been unable to fully expand his lung since 1982.

It should only ever be done if at all … on a fully expanded lung with no fluid and a smaller dosage. It is known in research that it is dangerous to do it at time of biopsies. As he had such marginal respiratory reserves (Dr Anthony Delaney ICU) he was incapable of ventilating after pleurodesis.

Don was given a Pleurodesis, with little knowledge of side effects, with fluid on the lung, at the same time biopsies were performed, with a lung unable to fully expand, with the biggest dose used and being a Quadriplegic of 25 years with "marginal respiratory reserves".

He would never survive this operation and the surgeon and cardio Thoracic should have and I believe would have had a fair idea that this was the case. I believe they realised he was in trouble a day after his operation and this explains their attitude.

Please take the time to read the articles below, all feely available to Dr and his team, ad as he is the author of one of the discussion letters, he would have been well aware of the controversy.

1. **Orion Laboratories PTY LTD.**
" Frequently asked questions – Sterile Talc.
This is important because it is from the company which produces the powder and the whole document would be relevant.

But this is really important
"Are there any Contraindications? **The main contraindication to pleurodesis is a lung that cannot expand thus not allowing the two irritated surfaces to come in contact with each other."**

" Are there any adverse effects? The most notable adverse effect is the pain associated with instillation. However respiratory complications and adult (my query…acute?) respiratory distress syndrome (ARDS) can develop (1.7). **Thus monitoring is recommended for detection or respiratory distress for 72 hours as ARDS has occurred up to 3 days after interpleural talc administration (1)."**

References are available on request from the company.

http://www.orion.net.au/faqs/tal00852_faq.pdf

2. **Oxygen cost of resistive-loaded breathing in quadriplegia.**

H. Manning, F. D. McCool, S. M. Scharf, E. Garshick and R. Brown
Department of Medicine, Brockton-West Roxbury Veterans Affairs Medical Center, Massachusetts 02132.

"We hypothesized that, in quadriplegia, chest wall distortion would increase the energy cost of ventilation. To assess this, we measured the oxygen cost of breathing (VO2 resp) and changes in chest wall configuration during inspiratory resistive-loaded breathing tasks in five quadriplegic and five normal subjects. Each subject performed three breathing tasks that spanned a range of work rates (Wtot). Configurational changes of the abdomen and upper, lower, and transverse rib cage were assessed with magnetometers. We found that 1) in both groups, VO2resp increased linearly with Wtot over the range of tasks performed, 2) the mean slope of the regression line of VO2resp vs. Wtot was greater for quadriplegic than for normal subjects (3.7 +/- 0.8 vs. 2.0 +/- 0.7 ml O2/J, P less than 0.01), 3) efficiency of breathing (Wtot/VO2resp) was less for quadriplegic than for normal subjects (1.9 +/- 0.6 vs. 3.5 +/- 1.4%, P less than 0.001), 4) during inhalation, upper and lower rib cages behaved similarly in the two groups, but the quadriplegic subjects had a decrease in transverse rib cage and a much greater increase in abdomen than normal subjects, and 5) functional residual capacity decreased in normal but not in quadriplegic subjects during the breathing tasks. **We conclude that the lesser efficiency of breathing in quadriplegia may be related to the elastic work of chest**

wall distortion, shorter mean operational diaphragm length, and possibly differences between normal and quadriplegic subjects in mechanical advantage of available inspiratory muscles. "

http://jap.physiology.org/cgi/content/abstract/73/3/825

3. **Respiratory Dysfunction and Management in Spinal Cord Injury**
Robert Brown MD, Anthony F DiMarco MD, Jeannette D Hoit PhD CCC-SLP, and Eric Garshick MD MOH
Introduction
Physiologic Effects of Spinal-Cord Injury on the Respiratory System
Mortality in Chronic Spinal-Cord Injury
Dyspnea
Interventions
Respiratory Muscle Training
Abdominal Binder
Ventilator-Assisted Speech
Respiratory Muscle Pacing
Assisted Cough
Mechanical Ventilation
Summary
"Respiratory dysfunction is a major cause of morbidity and mortality in spinal cord injury (SCI),
which causes impairment of respiratory muscles, reduced vital capacity, ineffective cough, reduction in lung and chest wall compliance, and excess oxygen cost of breathing due to distortion of the respiratory system."

"**Physiologic Effects of Spinal-Cord Injury on the Respiratory System**
Injuries above the level of the phrenic motoneurons (C3, 4, and 5) cause virtually complete paralysis of both the muscles of inhalation and exhalation and dependence on mechanical ventilation or phrenic-nerve stimulation. At lower levels of injury, the prospect of breathing without mechanical assistance is improved. Scanlon et al3 observed that within a month of injury there appears to occur a reduction in lung compliance that does not change during the year thereafter. This observation casts doubt on the previously held notion that reduced lung compliance in SCI is due to chronic lung injury from repeated infections. 4–10 The cause of the early reduction in lung compliance is unclear but has been ascribed partially to reduced lung volume and partially to changes in the mechanical properties of the lung from alterations in surfactant, which can occur rapidly with ventilation at low lung volume.3,9,11–13 Chest"

"In motorized-wheelchair users, the relatively high rate of breathlessness during talking may be related to difficulty interrupting breathing to manipulate phrasing and speech loudness, because their breathing is already greatly impaired.60,67"

"Those with complete injuries had a greater prevalenceof breathlessness than the others."
Don was C5C6 COMPLETE.

This article is quite large and its implications for the understanding of the marginal respiratory reserves of Quadriplegics without having any fluid needs to be understood for anyone doing a pleurodesis. The whole article concerning C5/C6 levels of Spinal Cord Injury needs to be understood.

http://www.aamr.org.ar/cms/archivos/secciones/kinesiologia/2006_lesion_medular.pdf

4. **Malignant Pleural Effusions** from Seminars in Respiratory and Critical Care Medicine Chemical Pleurodesis

"**Acute Respiratory Failure Associated with Talc Pleurodesis**
Concern has been raised about acute respiratory failure following talc pleurodesis. Because talc has been used since 1958 with an excellent success rate and safety profile, I reviewed the English language literature from 1958 through 2001 in an attempt to determine the incidence and causality of acute respiratory failure following talc pleurodesis by poudrage or slurry, when used for malignant effusions, nonmalignant effusions, or pneumothorax. Most reports were case series, with some series reporting over 350 patients with malignant effusions. The total number of talc poudrage and slurry pleurodeses reported was 4252. There were 43 (1%) episodes of acute respiratory failure. There were 41 (1.3%) of 3064 patients with acute respiratory failure reported with malignant pleural effusions, 2 (0.2%) of 1009 patients with pneumothorax, and 0 (0%) of 178 patients with nonmalignant pleural effusions.[24,25,31-45] After careful reading of these manuscripts, it was my opinion that 18 (0.4%) of the episodes of acute respiratory failure were probably related to talc; however, there were other circumstances that may have placed the patients at increased risk. Nine were treated with slurry and 9 with poudrage.[31,34,35,37,38,42-44] The average dose was 5.5 gm with a range of 2 to 10 gm. Sixteen of the 18 patients required mechanical ventilation and 6 died. Of these 18 patients, 1 had bilateral simultaneous pleurodeses, 2 followed mechanical pleurodesis, and 1 followed multiple pleural biopsies; these 5 patients may not have developed acute respiratory failure if bilateral simultaneous pleurodesis had not been performed or the pleura had not been abraded or biopsied, which may have resulted in a more rapid absorption of a greater concentration of talc into the systemic circulation."

"A retrospective review of complications of talc pleurodesis from Seattle (1993 to 1997), totaling 78 patients who had 89 pleurodeses, noted a number of respiratory complications following talc.[37] Talc slurry was used in 70 of the 89 procedures and

poudrage in the remaining 19. Five grams of talc was used in 85 of the pleurodeses. Complications reported were hypoxemia (9), ARDS (8), dyspnea (6), reexpansion pulmonary edema (3), and death (1). Seven patients developed ARDS with 8 pleurodesis procedures. One patient with AIDS and Pneumocystis carinii pneumonia-induced pneumothorax had bilateral simultaneous talc pleurodeses preceded by pleural abrasion. In the 6 other patients with malignant pleural effusions, 2 had pleural abrasion prior to talc poudrage, whereas 4 had only talc slurry pleurodesis. Therefore, it would have been more appropriate for the authors to state that, with 89 pleurodeses, 4 patients developed ARDS, which may have been solely related to talc. In the remaining 15 of 25 patients, no information was provided that could allow determination of the cause of the acute respiratory failure.

In my opinion, bilateral, simultaneous chemical pleurodesis should never be performed. Also, I believe that it is a relative contraindication to precede chemical pleurodesis with abrasion or multiple biopsies, which may allow more rapid movement of the chemical into the systemic circulation. Possible causes for acute respiratory failure following talc pleurodesis include the systemic inflammatory response syndrome (SIRS) or ARDS, reexpansion pulmonary edema, excessive premedication, severe comorbid disease, widespread malignant involvement of the lungs, terminal malignancy, sepsis from unsterile talc or poor chest tube technique, and excess talc (high dose or bilateral simultaneous pleurodesis). If talc is culpable, it may be due to talc with very small particle size[46] (the majority of the talc crystals being < 30 microns) or there is a contaminant or endotoxin in the talc.[47]"

"Several years ago, we demonstrated that radiolabeled tetracycline dispersed immediately and completely throughout the pleural space when instilled through a chest tube.[60] A follow-up randomized study, comparing the efficacy of tetracycline pleurodesis in patients who were rotated compared to those who remained supine, showed no difference in pleurodesis success, suggesting that there was no need to rotate patients when using a soluble agent such as tetracycline.[61] However, with talc in a slurry, I currently recommend that rotation be accomplished over a 1-hour period, moving the patient through right and left lateral decubitus positions, head of the bed at 45 to 60 degrees, Trendelenburg and supine, because dispersion may not be as complete as with a soluble agent."

"Time of Instillation and Chest Tube Removal

The dogma among clinicians who use chemical pleurodesis is that the agent should be instilled when the lung is fully expanded on radiograph and there is < 150 mL of daily drainage through the tube. It is also stated that the chest tube should be removed when there is < 100 to 150 mL drainage per 24 hours. In a randomized trial of 25 patients with malignant pleural effusion evaluating timely instillation and chest tube drainage, 15 patients were randomized to standard chest tube drainage and 10 patients to short-term chest tube drainage.[63] Patients in the standard group had the chest tube in place until there was lung reexpansion on chest radiograph and the volume of fluid drained from the chest tube was < 100 mL per 24 hours before 1500 mg of

tetracycline was instilled. The chest tube was removed in these patients when the amount of fluid drained was < 150 mL per 24 hours after the tetracycline was administered. In the 10 patients in the short-term group, the same dose of tetracycline was instilled as soon as the chest radiograph showed lung reexpansion and the effusion was drained, which was usually within 24 hours, regardless of the volume of tube drainage; the chest tube was removed the day after instillation of tetracycline. Pleurodesis success was 80% in each group, but the duration of chest tube drainage was significantly shorter (median 2 days, range 2-9 days) in the short-term chest tube group compared with the standard chest tube group (median of 7 days, range 3-19 days), ($p < 0.01$). This small randomized study suggests that, as soon as the lung is fully expanded on chest radiograph with an absence or minimal volume of fluid, the pleurodesis agent should be instilled, regardless of the volume of drainage through the chest tube; the chest tube should be removed the following day regardless of drainage. The use of this technique could substantially shorten the patient's hospital stay or could be done on an outpatient basis, both minimizing cost.

Recommendation for Pleurodesis

Factors that need to be considered before recommending chemical pleurodesis include response to therapeutic thoracentesis, general health of the patient, performance status,[64] pleural space anatomy by chest radiograph or chest CT, pleural space elastance,[17] the primary malignancy,[9] and pleural fluid pH.[65-68]

Absolute contraindications to pleurodesis include absence of relief of dyspnea on therapeutic thoracentesis, extensive trapped lung, or mainstem bronchial occlusion. Relative contraindications to pleurodesis include a terminal patient, widespread metastatic disease, poor performance status, active air leak, low pleural fluid pH, severe underlying lung disease**, and following extensive pleural abrasion or multiple biopsies."**

http://www.medscape.com/viewarticle/424726_9

5 What's New in ACS Surgery. From ACS Surgery: Principles & Practice

Posted 01/27/2006

Rafael S. Andrade, MD; Michael Maddaus, MD, FACS

Clinical evaluation, investigative studies, management, pleural anatomy, and pleural fluid physiology are discussed.

"The ideal talc dose has not been determined; the usual dose is 4 or 5 g. Talc pleurodesis with a 5 g dose has generally proved efficient and safe."

"Pain and fever are frequent side effects of talc pleurodesis, but the main concern is the possible development of acute lung injury (ALI) and respiratory failure. Respiratory failure occurs in approximately 1% to 4% of patients. The cause of respiratory failure secondary to talc pleurodesis is not clear and is probably related to multiple factors (e.g., talc dose, talc absorption, underlying lung disease, reexpansion pulmonary edema, systemic inflammatory response, tumor burden, and lymphatic obstruction)."

http://www.medscape.com/viewarticle/521708

6. **Talc Pleurodesis vs Iodopovidone** *Chest.* 2003;123:1318-1319.)
© 2003 American College of Chest Physicians
Yossef Aelony, MD, FCCP

Rancho Palos Verdes, CA

Correspondence to: Yossef Aelony, MD, FCCP, 25825 Vermont Ave South, Harbor City, CA 90710; e-mail: yaelony@dnamail.com

"To the Editor: ... The 9% incidence of ARDS referenced by Olivares-Torres et al[1] actually occurred in patients who had undergone surgical procedures, including pleural abrasion and talc application, suggesting that pleural abrasion may be a risk fact or for ARDS."

Rafael Laniado-Laborén, MD, MPH, FCCP

San Ysidro, CA

Correspondence to: Rafael Laniado-Laborín, MD, MPH, FCCP, PMB 953, 482 W San Ysidro Blvd, No. 2, San Ysidro, CA 92173; e-mail: rafaellaniado@hotmail.com

"To the Editor:

I thank Dr. Aelony for his comments on our article in *CHEST* (August 2002)[1] and appreciate the opportunity to respond. There are a few points in his letter that need clarification.

1. Safety of talc. For decades, talc, whether by poudrage or slurry, has been considered to be the most effective pleurodesis agent available.[2] Unfortunately, there is growing concern regarding the safety of talc administered intrapleurally.[3 4] In his letter, Dr. Aelony states that the calculated incidence of ARDS in patients undergoing talc pleurodesis ranges from 0.14 to 0.07% (*ie*, barely 1 case of ARDS per 1,000 patients treated with talc pleurodesis). However, in the editorial used as reference for these data,[2] the author actually presents an estimated incidence of 7 cases of ARDS per 1,000 patients treated

with talc pleurodesis. As we mention in our article, the reported rate of ARDS associated with talc pleurodesis has been as high as 9%. There are at least 32 cases in the literature of ARDS occurring after the administration of intrapleural talc. In eight instances, the patient died.[3] It seems that an important factor in the development of ARDS associated with talc pleurodesis is the size of the talc particle.[5] Although the risk of mesothelioma from talc pleurodesis is very small, the fact that the possibility exists provides another reason not to use talc for pleurodesis, especially in nonmalignant conditions. Iodopovidone has been extensively used in Mexico for almost 10 years[6] without reports of any serious side effects. Obviously, it should not be used in the presence of a bronchopleural fistula. Its passage into the bronchial tree *could* be associated with the development of ARDS, due to the low pH of talc. "

http://www.chestjournal.org/cgi/content/full/123/4/1318

7. **A Publication of the International Pleural Network Volume 1 Issue 1 January 2003 - International Pleural Newsletter.**
"Influence of particle size on extrapleural talc dissemination after talc slurry pleurodesis

J. Ferrer, J.F. Montes, M.A. Villarino, R.W.Light & J. Garcia-Valero **Chest 2002;122:1018-27**

Talc is one of the most commonly used pleurodesis agents. However, the safety of talc pleurodesis has recently been called into question after at least 32 reported cases of acute respiratory distress syndrome in the literature. It has been speculated that this pulmonary inflammatory syndrome is secondary to the extrapleural dissemination of the talc particles, and that talc preparations with small-sized talc particles are more likely to be systemically absorbed and produce subsequent pulmonary inflammation.
In this elegant study 30 rabbits underwent pleurodesis, 10 with normal talc, 10 with calibrated 'large' talc and 10 with saline (controls). The normal talc and the large talc preparations have mean particle diameters of 8.4μm and 12.0μm respectively. The rabbits were sacrificed at 24 hours and 7 days. Pleural inflammation, pulmonary and systemic talc particle deposition (particularly in the liver) was greater with normal talc than with calibrated 'large' talc. Both talc preparations were equally effective in achieving pleurodesis.
This study suggests that smaller sized talc particles are more likely to disseminate outside the pleural space and produce more systemic inflammation. However, the optimal size of talc particles for pleurodesis cannot be established from the present data. Human studies are urgently needed to confirm these findings.
Nick A Maskell Oxford, U.K. "

http://www.mesothelioma-lung-cancer.org/imig-newsletters/IntPleruaINews.pdf

8. Talc Should Not Be Used for Pleurodesis

Richard W. Light Saint Thomas Hospital, Vanderbilt University, Nashville, Tennessee

"At the present time, talc is one of the agents most commonly used for producing a pleurodesis in patients with either a spontaneous pneumothorax or a recurrent pleural effusion. However, questions have been raised concerning the safety of talc administered intrapleurally. In particular, there have been reports of acute respiratory distress syndrome (ARDS) occurring after talc is administered intrapleurally either as a slurry (1) or as an insufflation (5). There are at least 32 cases in the literature of ARDS occurring after administration of intrapleural talc, 17 after the use of talc slurry and the remaining 15 after talc insufflation (1). Within the first 48 h of receiving the talc, the patients developed ARDS and required mechanical ventilation. In eight instances the patient died (1, 4, 8).

The incidence of ARDS occurring after administration of intrapleural talc has varied markedly from series to series. Most of the reported cases have been from the United States. The highest incidence was that reported by Rehse and associates (6), who retrospectively reviewed 89 talc pleurodesis procedures in 78 patients. They reported that the incidence of respiratory complications or death was 33%; eight patients developed acute respiratory distress syndrome, one patient died, six patients developed dyspnea, and three patients developed re-expansion pulmonary edema (6). Although it has been suggested (10) that respiratory failure might be more common after larger doses of talc or talc slurry, Campos Milanez and coworkers reported that acute respiratory failure developed in 4 of 338 patients (1.2%) who received 2 g of insufflated talc for either recurrent pleural effusion or pneumothorax (5). It should be noted, however, that the reported incidence of respiratory complications is zero in some large series. Weissberg (10), from Israel, reported no incidences of acute respiratory distress in 360 patients who received talc pleurodesis, whereas Rodriguez-Panadero and Antony from Spain reported no cases of acute respiratory distress in 299 patients (11).

The mechanism or mechanisms by which talc produces acute lung injury is unknown. Talc is a pulverized, natural, foliated, hydrated magnesium silicate with the approximate chemical formula $Mg_3(Si_2O_5)_2(OH)_2$. Calcium, aluminum, and iron are always present in variable amounts. Every talc deposit is unique with regard to both chemistry and morphology. When talc is processed, it is passed through mesh to eliminate the larger sized talc particles. The size of the final talc preparation depends on the size of the mesh through which it has been passed. There are more than threefold differences in the median particle size of various talc preparations used for pleurodesis, and there are also marked variations in the contaminants present in various talc preparations (12). One hypothesis is that the acute pneumonitis is related to the systemic absorption of talc, with the subsequent elaboration of inflammatory mediators, and that smaller particles are more likely to be absorbed. This hypothesis is supported by the observations in the one case reported by Rinaldo and coworkers (1) and by Campos Milanez and associates (5), who reported that there were large

quantities of talc in the bronchoalveolar fluid of their patient, who presented with acute pneumonitis after talc pleurodesis. In addition, the one patient reported by Milanez Campos and colleagues, and who underwent an autopsy, had talc crystals present in almost every organ, including the ipsilateral and contralateral lung, brain, liver, kidney, heart, and skeletal muscle. Moreover, after talc is administered intrapleurally to rabbits (13) or rats (14), talc particles are found throughout the body.

From the above, it is evident that the intrapleural administration of talc, either as a slurry or as an insufflation, induces ARDS in a small percentage of patients and leads to the death of an occasional patient. Is the superiority of talc administration over other available methods of producing a pleurodesis sufficiently great to justify its continued used? Let us consider the cases separately for pleurodesis done in association with tube thoracostomy and pleurodesis done in association with thoracoscopy.

When pleurodesis is performed in conjunction with tube thoracostomy for a recurrent pleural effusion or pneumothorax, the main alternatives to talc slurry are a tetracycline derivative or bleomycin. Although it is generally accepted that talc slurry is most effective at producing a pleurodesis, there is no strong evidence that this is true. Two randomized studies (15, 16) comparing the efficacy of talc slurry and bleomycin were unable to demonstrate any significant difference in the success rates with the two agents. Heffner and associates, in reviewing the results of pleurodesis in 570 patients, were unable to demonstrate any significant difference in the success rates between talc, bleomycin, or the tetracycline derivatives (17).

Thoracoscopy plus the placement of a chest tube will lead to a pleurodesis in more than 50% of patients with a malignant pleural effusion. When two studies with 61 patients were combined, thoracoscopy plus a chest tube for a few days resulted in a pleurodesis in 38 patients (62%) (18, 19). The insufflation of talc in conjunction with thoracoscopy will result in successful pleurodesis in at least 90% of patients. An alternative to talc insufflation is mechanical abrasion of the pleura. Although there are no large series evaluating thoracoscopy with pleural abrasion in the treatment of malignant pleural effusion, it has been shown in dogs that mechanical abrasion is at least as good as talc in producing a pleurodesis when the pleura is normal (20). On the basis of the above, when an attempt is made to produce pleurodesis in conjunction with a thoracoscopic procedure, pleural abrasion followed by tube thoracostomy for a couple of days is recommended.

In conclusion, the administration of talc intrapleurally, either insufflated or as a slurry, can lead to the development of the acute respiratory distress syndrome and even death. Similar problems are not seen after the intrapleural administration of the tetracycline derivatives or bleomycin or after mechanical abrasion of the pleura. Because there is no convincing evidence that talc slurry is superior to either the tetracycline derivatives or bleomycin administered via a tube thoracostomy or that

talc insufflation is superior to mechanical abrasion of the pleura, talc should not be used for pleurodesis.

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9. **Pleurodesis: what agent should be used?**

Pleurodesis is indicated when one wishes to obliterate the pleural space. The indications for pleurodesis are a symptomatic recurrent pleural effusion or a spontaneous pneumothorax(1). Over the past 70 years many agents have been

injected intrapleurally in an attempt to create a pleurodesis. The agents used have included radioisotopes, quinacrine, antineoplastics (nitrogen mustard, bleomycin, mitoxantrone), tetracycline derivatives (tetracycline, doxycycline, minocycline), talc, erythromycin, sodium hydroxide, silver nitrate, iodopovidone, killed *orynebacterium parvum* and OK-432 which is an immunostimulant obtained from *Streptococcus pyogenes* (2).

The mechanism for pleurodesis with most of the agents listed above is thought to be the following: an agent is injected into the pleural space which injures the mesothelial cells lining the pleural space(2). As a result of the injury, pleural inflammation develops usually in association with a pleural effusion. If the injury is sufficiently severe, the resulting inflammation will lead to the formation of collagen and the visceral and parietal pleura will fuse producing a pleurodesis(2).

In the 1960's and 1970's antineoplastic agents were the most popular agents. Nitrogen mustard was most commonly used and was effective in up to 87% of patients(3). Originally it was thought that the efficacy of the antineoplastic agents was due to their antitumor effects. However, subsequently it was shown that pleurodesis occurred when the tumor was not controlled and the pleurodesis was attributed to the fibrosing effects of the drugs(2). In recent years, bleomycin has been the antineoplastic agent most commonly used for pleurodesis. This is not due to its greater efficacy, but rather to the fact that the pharmaceutic company who manufactures it completed the necessary paperwork to get it approved by the Federal Drug Administration in the United States.

It should be noted that bleomycin does not produce pleurodesis in experimental animals(4). Mitoxantrone is another antineoplastic agent which has been used as a pleurodesing agent. It is not recommended because doses sufficiently high to induce a pleurodesis in animals produce a cardiomyopathy(5). Of all the antineoplastics, nitrogen mustard at a dose of 0.8 mg/kg is the most effective in producing a pleurodesis in rabbits(6). When it was realized that it was the fibrosing effects rather than the antineoplastic effects of the agents that was responsible for producing the pleurodesis, non-specific irritants such as talc, tetracycline, and quinacrine were used for pleurodesis. In the 1980's tetracycline was the most commonly used agent primarily because a study in rabbits demonstrated that it was the most effective agent(7). However, in the late 1980's the company that produced parenteral tetracycline terminated its production. Subsequently it was shown that doxycycline and minocycline were comparable in efficacy to tetracycline(8,9).

When tetracycline became unavailable, the use of talc as a pleurodesis agent increased rapidly. Indeed, it is the agent most commonly used for pleurodesis at the present time(10). Talc can be administered either as an aerosol (insufflation) or a suspension (slurry). Talc is the choice of many physicians because it is inexpensive,

widely available and is perceived to be the most effective agent(11). The primary problem with talc is that it has been incriminated in causing the acute respiratory distress syndrome (ARDS) which is fatal in approximately one percent of patients who receive it intrapleurally(12).

The mechanism for the ARDS is not definitely known, but it has been hypothesized that it is due to the systemic absorption of small talc particles(13). Since the life expectancy of patients with malignancy is very limited, this would not necessarily mean that talc should not be used if it were significantly more effective than the other agents. Although it has been stated in the past that talc was 95% effective and was much more effective than other agents(11), this does not appear to be the case. In one analysis of 433 patients subjected to thoracentesis with talc, tetracycline derivatives or bleomycin, talc was no more effective than the other agents - all agents being approximately 80% effective(14). In a recent study from Australia, the insufflation of talc at thoracoscopy in 66 malignant pleural effusions resulted in completed control in only 52%(15). Therefore, other agents should be considered.

There are two other agents that are inexpensive and widely available that may prove to be excellent agents for pleurodesis - silver nitrate and iodopovidone. Vargas and coworkers(16,17) have shown that silver nitrate is at least as good as the tetracycline derivatives or talc in producing pleurodesis in rabbits. Moreover, they have shown that 20 ml of 0.5% silver nitrate produced control of 22 of 23 patients (95%) with malignant effusions (18). A recent article from Mexico reported that the intrapleural instillation of 20 ml 10% iodopovidone plus 80 ml normal saline resulted in complete control of the effusion 2 in 50 of 52 patients (96%) (19). In this study the iodopovidone was administered either through a chest tube or at the time of thoracostomy. Three patients did experience intense pleuritic pain and systemic hypotension after the instillation of the sclerosing agent, but they recovered without incident(19)

In view of the above, what agent should be used for pleurodesis in 2003? I prefer not to use talc because of the possibility that its intrapleural instillation can induce ARDS and the fact that it is no more effective than other agents. My agent of choice is doxycycline 500 mg. Acceptable alternatives are silver nitrate and iodopovidone. If I wanted to use an antineoplastic, I would use nitrogen mustard at a dose of 0.8 mg/kg.

Richard W. Light, M.D.
Director, Pulmonary Disease Program Saint Thomas Hospital
and Professor of Medicine Vanderbilt University, Nashville, TN
Reprint Requests to:
Director of Pulmonary Disease Program
Saint Thomas Hospital
4220 Harding Road

Nashville, Tennessee 37205
Phone: (615) 222-3043, Fax (615) 222-6564
E-Mail RLIGHT98@yahoo.com

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10. Influence of talc dose on extrapleural talc dissemination after talc pleurodesis.

Montes JF, Ferrer J, Villarino MA, Baeza B, Crespo M, Garcia-Valero J.

Departament deBiologia Cel.lular, Facultat de Biologia, Universitat de Barcelona, Barcelona, Spain.

This study was designed to ascertain, in a rabbit model, extrapleural talc deposition and the related inflammatory response after talc slurry pleurodesis with two clinical doses, 200 and 50 mg/kg. Histopathologic evaluations

revealed that whereas numerous rabbits receiving a high dose had talc in the ipsilateral (70%) and contralateral (55%) lung, mediastinum (90%), pericardium (30%), and liver (25%), a small number of animals treated with a low dose showed talc in the ipsilateral lung (10%) and mediastinum (20%) and none in the contralateral lung, pericardium, or liver. Hematologic and immunocytochemical analyses showed that a systemic inflammatory response develops shortly after pleurodesis with a high talc dose involving massive accumulation of neutrophils and macrophages in lung tissue. Zymography also revealed that the pulmonary expression of matrix metalloproteinases 2 and 9 was up-regulated in both lungs in a dose-dependent manner soon after talc instillation. Furthermore, microscopic examination of lung specimens revealed that the higher the dose of talc, the greater the development of both fibrotic visceral pleural thickening and foreign-body granulomas. **These findings show pleurodesis with a high talc dose to be associated with an increased risk of extrapleural talc deposition, which may originate undesirable acute and chronic inflammatory responses.**

PMID: 12773332 [PubMed - indexed for MEDLINE]

http://www.ncbi.nlm.nih.gov/sites/entrez?Db=pubmed&Cmd=ShowDetailView&TermToSearch=12773332&ordinalpos=1&itool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_RVAbstractPlus

11. Influence of Talc Dose on Extrapleural Talc Dissemination after Talc Pleurodesis

Juan F. Montes, Jaume Ferrer, María A. Villarino, Bernat Baeza, Marta Crespo and José García-Valero

Departament de Biologia Cel·lular, Facultat de Biologia, Universitat de Barcelona; and Servei de Pneumologia, Hospital General Universitari Vall d'Hebron, Universitat de Barcelona, Barcelona, Spain

Correspondence and requests for reprints should be addressed to Jaume Ferrer, M.D., Servei de Pneumologia, Hospital General Universitari Vall d'Hebron, Passeig Vall d'Hebron 119–129, E-08035 Barcelona, Spain. E-mail: jjferrer@vhebron.net

Concerning local inflammatory response, histopathologic analysis of lung samples showed neutrophils and macrophages to be the main cell types involved in the acute inflammatory response developing in lung tissues soon after talc instillation. These results add to previous observations revealing a neutrophilic reaction (49) and perivascular mononuclear infiltrates (27) in lung parenchyma of talc-treated rabbits and are in line with several studies describing a massive influx of neutrophils and macrophages in high-volume exudative pleural effusions shortly after talc pleurodesis both in rabbits (27, 50) and humans (51, 52). Moreover, our current histopathologic,

immunocytochemical, and zymographic findings permitted us to determine that the tissue accumulation of these two types of inflammatory cells was considerably greater in the lungs of animals receiving a high talc dose than in those treated with a low dose.

In addition to the aforementioned acute inflammatory responses, talc pleurodesis was also associated with undesirable chronic pulmonary disorders consisting of fibrotic visceral pleural thickening and foreign-body granulomatous reactions. Nevertheless, microscopic examination of lung specimens revealed that the lower the dose of talc, the lower the development of both visceral pleural thickening and granulomas. These results concur essentially with the findings of Lee and coworkers (53) who, 1 week after a 400-mg/kg talc dose instillation in the rabbit model, reported a greater visceral pleural thickening (85 μm) than that obtained with 200 mg/kg in this study (72.3 μm).

For all these reasons and given that, in clinical practice, no difference in efficacy is observed between low (2–5 g) and high (10–14 g) talc doses (3, 4) and that most patients developing ARDS received high talc doses (10, 14), we agree with the opinion that only the lower dose should be used (7). Likewise, we agree that talc pleurodesis should not be performed after procedures that would enable more rapid and increased concentrations of talc to enter the ipsilateral lung and systemic circulation, such as pleural abrasion or multiple biopsy procedures (7, 17).

In conclusion, the present study demonstrates that pleurodesis performed with a high dose of talc is associated with an increased risk of both pulmonary and extrapulmonary talc deposition, which may originate undesirable acute and chronic inflammatory responses.

http://ajrccm.atsjournals.org/cgi/content/full/168/3/348

Don was given 10g – a high dose.

All of the discussion below is important because it is dr Mathur who did the surgery on Don and it appears he favours high dose talc

12.American Journal of Respiratory and Critical Care Medicine Vol 169. pp. 1074-1075, (2004)
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Correspondence

Systematic Response to Talc Pleurodesis

To the Editor:

We read with interest the recent article by Montes and colleagues (1) describing increased systemic talc deposition in high- as opposed to low-dose talc slurry pleurodesis. Whereas the authors clearly support the theory that severe complications after pleurodesis are due to disseminated talc, they correctly state that this hypothesis has not been proved. We report a fatal case of talc pleurodesis syndrome in which complete autopsy failed to demonstrate systemic dissemination of talc.

An 84-year-old woman with a history of polycythemia rubra vera (controlled with venesection) presented with a right-sided pleural effusion. Video-assisted thoracoscopy with biopsy of the parietal pleura and poudrage with high-dose talc was undertaken. Eighteen hours after surgery she became hypotensive and hypoxic. Chest radiograph showed patchy bilateral infiltrates in both mid and lower zones. Although afebrile, her white cell count increased dramatically from 10.9 x 10^9/L before surgery to 49.4 x 10^9/L on the second postoperative day. She died 58 hours after surgery with intractable hypotension, severe hypoxia, and acute renal failure. Results of blood and sputum cultures were negative.

At autopsy, extreme care was taken to stop talc from the right pleural cavity contaminating other organs. Despite extensive histologic examination of all organs, including many blocks from each lobe of both lungs, no talc was demonstrable outside the massively inflamed right pleural cavity. The lungs were hyperemic and the alveolar spaces distended by neutrophils—morphologically very similar to early bacterial pneumonia. No other cause of hypoxia or vascular collapse was found (the pleural effusion was shown to be due to an early mesothelioma).

Given the degree of pleural inflammation and systemic neutrophilia in this case, we postulate that vascular collapse was due to a systemic inflammatory response syndrome in the absence of circulating talc. Furthermore, we suggest that pleural inflammation may trigger pulmonary inflammation through paracrine and circulating factors without the need for talc to enter the lungs. We propose that this "aseptic pneumonitis" is the cause of opacification and hypoxia seen in talc pleurodesis syndrome rather than diffuse alveolar damage, the usual histologic correlate of acute respiratory distress syndrome, to which it is often attributed without pathologic correlation.

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.

Anthony J. Gill, Manu N. Mathur and Susan F. Tattersall

Royal North Shore Hospital Sydney, Australia

FOOTNOTES

Conflict of Interest Statement: A.J.G., M.N.M., and S.F.T. have no declared conflict of interest.

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From the Authors:

The term "acute respiratory distress syndrome" (ARDS) refers to a clinical picture consisting of dyspnea, tachypnea, cyanosis, and diffuse alveolar infiltrates on chest radiograph. Pathologic findings include diffuse alveolar damage with neutrophils, macrophages, erythrocytes, hyaline membranes, and protein-rich edema fluid in the alveolar spaces, capillary injury and disruption of the alveolar epithelium (1). Cases of acute lung failure occurring after talc pleurodesis have been considered to be ARDS owing to a similar clinical pattern, but pathologic descriptions in these cases have not been reported. The hypothesis that pulmonary talc dissemination accounts for acute lung failure observed after talc pleurodesis is supported by the following facts: (*1*) whenever investigated, talc has been found in all patients with acute lung failure after talc pleurodesis, whether in lung or bronchoalveolar lavage samples, but not in patients without acute lung failure (*see* our article [2] for more details); (*2*) acute lung failure has not been described after nontalc pleurodesis; (*3*) in animal studies, talc dissemination to the lung has been reported, especially at high doses (2) and with smaller talc particles (3); (*4*) most patients undergoing acute lung failure after talc pleurodesis received talc from the United States, where smaller talc particles are used (*see* DISCUSSION and REFERENCES in our article [2]).

The case reported by Gill and colleagues clearly describes a lethal acute lung failure after talc pleurodesis in which no talc was found in the lungs of the patient. In our opinion, there may be two explanations for this fact. First, several lung problems may account for the clinical acute respiratory failure observed in the patient reported by Gill and colleagues. Characteristic pathologic features of ARDS are lacking, so this patient could have had another process. As an example, negativity of cultures does not preclude the possibility that this older woman with bilateral infiltrates, blood leukocytosis, and neutrophil lung infiltration had a lung infection. Second, talc produces pleurodesis by inflaming the pleura, and therefore acute lung failure could be caused either by a direct effect of talc particles disseminated to the lung or indirectly by inflammatory mediators released from the inflamed pleura.

Jaume Ferrer[a], Juan F. Montes[b] and José García-Valero[b]

[a] Hospital Universitari Vall d'Hebron Barcelona, Spain
[b] Universitat de Barcelona Barcelona, Spain

FOOTNOTES

***Conflict of Interest Statement*:** J.F., J.F.M., and J.G-V. have no declared conflict of interest.

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***To the Editor*:**

The article by Montes and colleagues (1) significantly and importantly relates pleural talc doses in *rabbits* to the animal's response. Higher doses of talc were associated with greater talc migration and created local and distant inflammatory responses. The authors' connection of these findings to the reported development of acute respiratory distress syndrome (ARDS) in humans is germane.

We report here the first case where a *human* served as her own control after ARDS occurred after a high dose of pleural talc insufflation (7.5–10 g). When 3 g of the same talc was administered to the contralateral thorax, ARDS did not develop (2).

Dyspnea due to recurrent left malignant pleural effusion developed in a 59-year-old woman 11 years after mastectomy for breast cancer. At thoracoscopy—for pleurodesis—the pleura was covered with 1- to 10-mm tumor nodules. During the procedure, an error was made in talc insufflation, which by protocol was to be 10 ml (5 g) or less. This resulted in 15 to 20 ml (7.5–10 g) of talc insufflation. After the procedure, the patient was weak, dyspneic, and febrile. Fever persisted for 10 days. The chest tube was removed after 72 hours when drainage was less than 150 ml per 24 hours (total drainage 650 ml over 72 hours). On the fourth day after the procedure,

worsening respiratory distress led to intubation and mechanical ventilation for 7 days. ARDS was diagnosed, with slow improvement to hospital discharge on Day 31 of hospital stay, and eventual recovery.

Seven months later, a symptomatic right-sided malignant effusion developed. Chest computed tomography scan showed a successful left pleurodesis. After a right-sided thoracoscopy and insufflation of 3 g talc, the patient's hospital course was uneventful with discharge on the third postoperative day. Radiographs 50 days later showed a partly successful pleurodesis; no further thoracenteses were needed. Her talc dosages were calculated to be 142 to 189 mg/kg on the left and 57 mg/kg on the right, which coincidentally are comparable with the rabbit study of 200 and 50 mg/kg doses (1).

We believe this case presents further evidence that talc overdosing may cause ARDS. Although our talc (Spectrum Chemical Supply, Gardena, CA) has a relatively small mean diameter of 5.5 μm, prospective data entry of 286 consecutive thoracoscopic talc poudrages and 9 talc slurry treatments revealed no other case of ARDS (2). As the authors—and many others—indicate, doses greater than 5 g in talc pleurodesis should be avoided.

Yossef Aelony

Southern California Permanente Medical Group Harbor City, California

FOOTNOTES

***Conflict of Interest Statement*:** Y.A. has no significant financial interest in the subject.

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***From the Authors*:**

The case presented by Dr. Aelony suggests that acute lung failure after talc pleurodesis is dose-dependent. Because, as demonstrated in our study, pulmonary talc dissemination after pleurodesis is also dose-dependent in the rabbit model (1), Aelony's report further supports the hypothesis that acute lung failure and lung talc

dissemination are related. To definitely prove that, in human beings, talc overdose may cause acute lung failure, randomized studies with different talc doses should be performed. However, it is obvious that the low frequency of acute lung failure and also ethical reasons preclude these studies from being performed. In the future, more studies on pulmonary histology and plasma levels of inflammatory cytokines in patients undergoing acute lung failure after talc pleurodesis should be done. Meanwhile, we agree with Dr. Aelony that doses less than 5 g should only be used in talc pleurodesis, and talc should not be administered when pleural biopsy is performed during pleurodesis.

Jaume Ferrer[a], Juan F. Montes[b] and José García-Valero[b]

[a] Hospital Universitari Vall d'Hebron Barcelona, Spain
[b] Universitat de Barcelona Barcelona, Spain

FOOTNOTES

Conflict of Interest Statement: J.F., J.F.M., and J.G-V. have no declared conflict of interest.

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13. Talc Should Not Be Used for Pleurodesis

Richard W. Light

Saint Thomas Hospital, Vanderbilt University, Nashville, Tennessee

At the present time, talc is one of the agents most commonly used for producing a pleurodesis in patients with either a spontaneous pneumothorax or a recurrent pleural effusion. However, questions have been raised concerning the safety of talc administered intrapleurally. **In particular, there have been reports of acute respiratory distress syndrome (ARDS) occurring after talc is administered intrapleurally either as a slurry (1) or as an insufflation (5). There are at least 32 cases in the literature of ARDS occurring after administration of intrapleural talc, 17 after the use of talc slurry and the remaining 15 after talc insufflation (1). Within the first 48 h of receiving the talc, the patients developed ARDS and required mechanical ventilation. In eight instances the patient died (1, 4, 8).**

The incidence of ARDS occurring after administration of intrapleural talc has varied markedly from series to series. Most of the reported cases have been from the United States. The highest incidence was that reported by Rehse and associates (6), who retrospectively reviewed 89 talc pleurodesis procedures in 78 patients. **They reported that the incidence of respiratory complications or death was 33%; eight patients developed acute respiratory distress syndrome, one patient died, six patients developed dyspnea, and three patients developed re-expansion pulmonary edema (6).** Although it has been suggested (10) that respiratory failure might be more common after larger doses of talc or talc slurry, Campos Milanez and coworkers reported that acute respiratory failure developed in 4 of 338 patients (1.2%) who received 2 g of insufflated talc for either recurrent pleural effusion or pneumothorax (5). It should be noted, however, that the reported incidence of respiratory complications is zero in some large series. Weissberg (10), from Israel, reported no incidences of acute respiratory distress in 360 patients who received talc pleurodesis, whereas Rodriguez-Panadero and Antony from Spain reported no cases of acute respiratory distress in 299 patients (11).

The mechanism or mechanisms by which talc produces acute lung injury is unknown. Talc is a pulverized, natural, foliated, hydrated magnesium silicate with the approximate chemical formula $Mg_3(Si_2O_5)_2(OH)_2$. Calcium, aluminum, and iron are always present in variable amounts. Every talc deposit is unique with regard to both chemistry and morphology. When talc is processed, it is passed through mesh to eliminate the larger sized talc particles. The size of the final talc preparation depends on the size of the mesh through which it has been passed. There are more than threefold differences in the median particle size of various talc preparations used for pleurodesis, and there are also marked variations in the contaminants present in various talc preparations (12). One hypothesis is that the acute pneumonitis is related to the systemic absorption of talc, with the subsequent elaboration of inflammatory mediators, and that smaller particles are more likely to be absorbed. This hypothesis is supported by the observations in the one case reported by Rinaldo and coworkers (1) and by Campos Milanez and associates (5), who reported that there were large quantities of talc in the bronchoalveolar fluid of their patient, who presented with acute pneumonitis after talc pleurodesis. In addition, the one patient reported by Milanez Campos and colleagues, and who underwent an autopsy, had talc crystals present in almost every organ, including the ipsilateral and contralateral lung, brain, liver, kidney, heart, and skeletal muscle. Moreover, after talc is administered intrapleurally to rabbits (13) or rats (14), talc particles are found throughout the body.

From the above, it is evident that the intrapleural administration of talc, either as a slurry or as an insufflation, induces ARDS in a small percentage of patients and leads to the death of an occasional patient. Is the superiority of talc administration over other available methods of producing a pleurodesis sufficiently great to justify its continued used? Let us consider the cases separately for pleurodesis done in association with tube thoracostomy and pleurodesis done in association with thoracoscopy.

When pleurodesis is performed in conjunction with tube thoracostomy for a recurrent pleural effusion or pneumothorax, the main alternatives to talc slurry are a tetracycline derivative or bleomycin. Although it is generally accepted that talc slurry is most effective at producing a pleurodesis, there is no strong evidence that this is true. Two randomized studies (15, 16) comparing the efficacy of talc slurry and bleomycin were unable to demonstrate any significant difference in the success rates with the two agents. Heffner and associates, in reviewing the results of pleurodesis in 570 patients, were unable to demonstrate any significant difference in the success rates between talc, bleomycin, or the tetracycline derivatives (17).

Thoracoscopy plus the placement of a chest tube will lead to a pleurodesis in more than 50% of patients with a malignant pleural effusion. When two studies with 61 patients were combined, thoracoscopy plus a chest tube for a few days resulted in a pleurodesis in 38 patients (62%) (18, 19). The insufflation of talc in conjunction with thoracoscopy will result in successful pleurodesis in at least 90% of patients. An alternative to talc insufflation is mechanical abrasion of the pleura. Although there are no large series evaluating thoracoscopy with pleural abrasion in the treatment of malignant pleural effusion, it has been shown in dogs that mechanical abrasion is at least as good as talc in producing a pleurodesis when the pleura is normal (20). On the basis of the above, when an attempt is made to produce pleurodesis in conjunction with a thoracoscopic procedure, pleural abrasion followed by tube thoracostomy for a couple of days is recommended.

In conclusion, the administration of talc intrapleurally, either insufflated or as a slurry, can lead to the development of the acute respiratory distress syndrome and even death. Similar problems are not seen after the intrapleural administration of the tetracycline derivatives or bleomycin or after mechanical abrasion of the pleura. Because there is no convincing evidence that talc slurry is superior to either the tetracycline derivatives or bleomycin administered via a tube thoracostomy or that talc insufflation is superior to mechanical abrasion of the pleura, talc should not be used for pleurodesis.

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14. **The Journal of Thoracic and Cardiovascular Surgery, Vol 85, 523-526,**
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ARTICLES

Adult respiratory distress syndrome following intrapleural instillation of talc

JE Rinaldo, GR Owens and RM Rogers

After intrapleural instillation of talc for sclerosis of malignant pleural effusions, dyspnea occurred in three patients, progressed gradually over 72 hours, and culminated in acute respiratory failure characterized by bilateral diffuse pulmonary infiltrates with normal pulmonary artery occlusion pressures. Two patients recovered and one died. The chronological similarity of the sequence of fever, dyspnea, and respiratory failure in the absence of documented infection or other conditions that predispose to the adult respiratory distress syndrome (ARDS) suggests that intrapleural talc may have induced the syndrome in these patients through unknown mechanisms. This experience emphasizes that other agents are preferable for initial attempts to promote pleural symphysis in the palliation of recurrent malignant effusions. When talc is used in patients who are unresponsive to tetracycline, we suggest clinical monitoring for respiratory compromise for 72 hours after the procedure.

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(Yet Don was a Quadriplegic of 25 years with as Dr Delaney said "Marginal respiratory reserves" and he was on 6 hourly observations -)

15. **Sclerosol – Official FDA Sclerosol information, side effects and uses.**

Generic Name: sterile talc
Dosage Form: Powder

Prescribing Information

For Intrapleural Administration Only

Shake Well Immediately Before Using

Sclerosol Description

Sclerosol® Intrapleural Aerosol (sterile talc powder 4 g) is a sclerosing agent for intrapleural administration supplied as a single-use, pressurized spray canister with two delivery tubes of 15 cm and 25 cm in length. Each canister contains 4.0 g of talc, either white or off-white to light grey, asbestos-free, and brucite-free grade of talc of controlled granulometry. The composition of the talc is ≥ 95% talc as hydrated magnesium silicate. The empirical formula is $Mg_3 Si_4 O_{10} (OH)_2$ with molecular

weight of 379.3. Associated naturally occurring minerals include chlorite (hydrated aluminum and magnesium silicate), dolomite (calcium and magnesium carbonite), calcite (calcium carbonate) and quartz. Talc is practically insoluble in water, and in dilute solutions of acids and alkali hydroxides. The canister and delivery tubes have been sterilized by gamma irradiation. The aerosol propellant contained in Sclerosol® Intrapleural Aerosol is dichlorodifluoromethane (CFC-12) with 26 g present per canister. The canister delivers 0.4 g of talc per second through the valve and the product contains no other excipients.

Sclerosol - Clinical Pharmacology

Mechanism of Action:

The therapeutic action of talc instilled into the pleural cavity is believed to result from induction of an inflammatory reaction. This reaction promotes adherence of the visceral to the parietal pleura, obliterating the pleural space and preventing reaccumulation of pleural fluid. The extent of talc systemically absorbed after intrapleural administration has not been adequately studied. **Systemic exposure could be affected by the integrity of the visceral pleura, and therefore could be increased if talc is administered immediately following lung resection or biopsy**.

Clinical Studies

The data demonstrating safety and efficacy of talc in the treatment of malignant pleural effusions are derived from the published medical literature. The following four trials were prospective, randomized studies of talc vs. a concurrent control, and provide sufficient detail for evaluation, including a clear, readily determined definition of response (no fluid reaccumulation by chest roentgenogram at one month or greater) and information allowing an analysis of all patients randomized. Talc was statistically significantly superior to the control arms in evaluable patients across the studies.

Indications and Usage for Sclerosol

Sclerosol® Intrapleural Aerosol, administered by aerosol during thoracoscopy or open thoracotomy, is indicated to prevent recurrence of malignant pleural effusions in symptomatic patients.

General:

1)Future procedures. The possibility of future diagnostic and therapeutic procedures involving the hemithorax to be treated must be considered prior to administering Sclerosol® Intrapleural Aerosol. Sclerosis of the pleural space may preclude subsequent diagnostic procedures of the pleura on the treated side. Talc sclerosis may complicate or preclude future ipsilateral lung resective surgery, including pneumonectomy for transplantation purposes.

2)Use in potentially curable disease. **Talc has no known antineoplastic activity and should not be used for potentially curable malignancies where systemic therapy would be more appropriate, e.g., a malignant effusion secondary to a potentially curable lymphoma.**

3)Potential pulmonary complications. Acute pneumonitis or acute respiratory distress syndrome (ARDS) have rarely been reported in association with intrapleural talc administration. Whether these were causally related to talc is unclear. In none of the reported cases was talc applied thoracoscopically or by insufflation. Three of four case reports of ARDS have occurred after treatment with 10 g of talc administered via intrapleural chest tube instillation. One patient died one month post treatment and two patients recovered without further sequelae.

Intravenous administration of talc is a well-recognized cause of pulmonary hypertension and pulmonary lung parenchymal disease, but these complications have not been reported after intrapleural administration. Pulmonary diseases, e.g., silicosis or asbestosis-like diseases, chronic bronchitis, bronchogenic carcinoma, and pleural plaques have been reported in association with inhaled talc.

4)Contents under pressure. The contents of the Sclerosol® Intrapleural Aerosol (sterile talc powder) canister are under pressure. The canister must not be punctured and should not be used or stored near heat or open flame.

Drug Interactions: It is not known whether the effectiveness of a second sclerosing agent after prior talc pleurodesis would be diminished by the absorptive properties of talc.

Carcinogenesis, Mutagenesis, Impairment of Fertility: Studies on the carcinogenicity of talc have been performed using non-standard designs, which prevent firm conclusions on its carcinogenicity. With single intraperitoneal administration to mice at 20 mg and observation for at least 6 months, or 4 weekly doses administered intraperitoneally at 25 mg/dose to rats with observation for at least 84 weeks, tumor incidence was not increased. In these studies, the talc and its asbestos content were not characterized. Genotoxicity was assessed in cultures of rat pleural mesothelial cells (RPMC), as unscheduled DNA syntheses (UDS) and sister chromatid exchanges (SCEs). None of the talc samples (which were asbestos free) enhanced UDS or SCEs

in treated cultures. No information is available on impairment of fertility in animals by talc.

Pregnancy: Pregnancy category B. An oral administration study has been performed in the rabbit at 900 mg/kg, approximately 5-fold higher than the human dose on mg/m2 basis, and has revealed no evidence of teratogenicity due to talc. There are, however, no adequate and well-controlled studies in pregnant women. Because animal reproduction studies are not always predictive of human response, this drug should not be used during pregnancy unless it is clearly needed.

Pediatric Use: The safety and efficacy of Sclerosol Intrapleural Aerosol® (sterile talc powder) in pediatric patients have not been established.

Geriatric Use: The mean and median ages of patients treated with talc in the clinical studies table were 50-62 years. No analyses to specifically evaluate the safety and efficacy in the geriatric population have been reported.

Adverse Reactions

Talc administration has been described in more than 1500 patients reported in the medical literature. Patients with malignant pleural effusions were treated with talc via poudrage or slurry. In general, with respect to reported adverse experiences, it is difficult to distinguish the effects of talc from the effects of the procedure(s) associated with its administration. The most reported common adverse experiences were fever and pain. Almost all of the cases of fever, and over half of the cases of pain, were in patients who received diagnostic biopsies at the time of talc administration.

Infections: Empyema was a rare complication of talc administration and/or the procedure. Biopsies had been obtained prior to onset in over half the reported cases.

Respiratory: Rare instances of pneumonia, ARDS, dyspnea, bronchopleural fistula, hemoptysis, and pulmonary emboli have been reported.

Cardiovascular: Tachycardia, myocardial infarction, hypotension, hypovolemia, and asystolic arrest associated with surgery and/or anesthesia have been rarely reported.

Delivery Procedure: Adverse reactions due to the delivery procedure and the chest tube may include: infection at the site of thoracostomy or thoracoscopy, localized bleeding, and subcutaneous emphysema.

Chronic Toxicity: Lange et al. (Thorax 1988;43:559) reported on 114 consecutive cases of idiopathic spontaneous pneumothorax treated with talc poudrage (60 patients), or simple drainage (54 patients) via an intercostal tube. Pulmonary function tests (FEV1, VC, TLC, and RV) 22 go 35 years after treatment, showed no significant differences in the incidence of pleural changes between the two groups.

Two patients treated with talc poudrage had more extensive pleural thickening with calcification. The mean total lung capacities were 89% of predicted in the talc group and 96% in the drainage only group. Fourteen patients (12 lifelong heavy smokers, 2 non-smokers) had airflow limitation (5 severe). Source and purity of the talc used was not reported. No cases of mesothelioma were reported. One case report noted the occurrence of adenocarcinoma of the chest wall two years after pleurodesis following 10 g of 1% iodized talc (administered for recurrent pneumothorax).

Overdosage

Overdosages have not been reported. See PRECAUTIONS: 3) Potential pulmonary complications.

Sclerosol Dosage and Administration

Sclerosol® Intrapleural Aerosol (sterile talc powder) is administered after adequate drainage of the effusion. It has been suggested that success of the pleurodesis is related to the completeness of the drainage of the pleural fluid, as well as full reexpansion of the lung, both of which will promote symphysis of the pleural surfaces.

The usual dosage of Sclerosol® Intrapleural Aerosol (sterile talc powder) is a single 4-8 g dose delivered intrapleurally from the spray canister (1-2 cans), which delivers talc at a rate of 0.4 g per second.

ADMINISTRATION PROCEDURE

Shake canister will before usage. Remove protective cap and securely attach actuator button with its delivery tube (either 15 cm or 25 cm) to the valve stem of canister.

Insert delivery tube through pleural trocar, taking care not to place the distal end of the delivery tube adjacent to the lung parenchyma or directly against the chest wall. While firmly holding the delivery tube and pleural trocar together in one hand, gently apply pressure to the actuator button on the canister. Sclerosol Intrapleural Aerosol® is not delivered by metered dose, but depends on the extent and duration of manual compression of the actuator button on the canister. The distal end of the delivery tube should be pointed in several different directions, while short bursts are administered in order to distribute the talc powder equally and extensively on all visceral and parietal pleural surfaces. For optimal distribution, always maintain the Sclerosol Intrapleural Aerosol® (sterile talc powder) canister in the upright position. After application, discard the canister and delivery tube. The duration of chest tube drainage following talc sclerosis is dictated by the clinical situation.

How is Sclerosol Supplied

NDC 63256-100-30: Sclerosol® Intrapleural Aerosol (sterile talc powder) contains 4.0 g of talc suspended in 26 g of inert propellant in a single-use aluminum canister. The canister if fitted with a continuous spray valve which delivers approximately 0.4 g of talc per second. This canister, attached to an actuator button, and two delivery tubes of 15 cm and 25 cm length, are supplied in a sterile, flexible plastic peel pack.

STORAGE: Warning: Contents under pressure. Do not puncture or incinerate container. Store between 59°F - 86°F (15°C - 30°C). Protect against sunlight and do not expose to a temperature above 120° F (49° C), or the canister may rupture. Avoid freezing. Shake well before using.

Revised: 10/2006

http://www.drugs.com/pro/sclerosol.html?printable=1

16. TALC SHOULD NOT BE USED FOR PLEURODESIS IN PATIENTS WITH NONMALIGNANT PLEURAL EFFUSIONS

To the Editor :

In the debate regarding the use of talc in pleurodesis, respiratory failure after intrapleural injection was cited as that complication potentially limiting employment of this agent (1, 2). We agree with this appraisal in the treatment of patients with malignant recurrent effusions. However, there should continue to be concern regarding the use of talc for pleurodesis in individuals with nonmalignant pleural effusions and spontaneous pneumothorax. This dilemma results from a possible increased risk of malignant mesothelioma in those patients treated with talc. Consequently, an alternative agent should be employed in any individual without malignancy requiring pleurodesis.

Talc is not a uniform substance, and varies significantly in size and chemical composition, with the latter depending on geologic origin. This sheet silicate can be contaminated by asbestos. An association between carcinogenesis and exposure to asbestos included in talc appears credible. Certainly, noncarcinogenic effects of

asbestos (pleural plaque formation) have been reported in patients instilled with talc for pleurodesis. The paucity of evidence of malignant mesothelioma occurring after the use of talc for pleurodesis may reflect either an inadequate latency period or an insufficient number in the investigations conducted. Assuming a risk of the same magnitude as that seen in the cohort of asbestos-exposed insulation workers (3), less than one case of mesothelioma would have been expected in the two investigations of patients exposed to talc used in pleurodesis (4, 5). However, case reports of malignant mesothelioma after occupational exposure to talc suggest a potential association (6). Furthermore, epidemiologic studies demonstrate an excess mortality from lung and pleural carcinomas in talc miners and millers, while animal studies confirm an induction of mesothelioma after intrapleural injection of talc.

The assertion that contemporary purified preparations of talc do not contain asbestos, therefore eliminating a risk of mesothelioma, should be closely examined prior to its acceptance for clinical application. The methodology used to confirm the lack of asbestiform minerals in a finished product (i.e., X-ray diffraction, optical microscopy, and electron microscopy techniques) and its sensitivity must be provided. Even if the product is "asbestos-free," the mechanism of cancer induction by asbestos (i.e., metal-catalyzed radical generation) is similarly pertinent to talc and the occurrence of fibrous forms of the sheet silicate itself (Figures E1 and E2 in the online data supplement to this letter) raises issues about clearance and long-term safety. Simply stating that the talc is "asbestos-free" should not release us from a responsibility to the patient, especially when safe alternatives are available.

Andrew J. Ghio

United States Environmental Protection Agency, Chapel Hill, North Carolina

Victor Roggli

Duke University Medical Center, Durham, North Carolina

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From the Authors:

I appreciate the comments of Drs. Ghio and Roggli concerning our article. I agree that talc should not be used to produce pleurodesis in patients with nonmalignant diseases such as spontaneous pneumothorax or recurrent nonmalignant pleural effusion. If talc should not be used to produce pleurodesis in patients with malignant disease because it might produce acute respiratory failure, it should not be used for pleurodesis in other situations for the same reasons.

Drs. Ghio and Roggli maintain that another reason talc should not be used in patients with nonmalignant disease is the possible increased risk of mesothelioma after the administration of talc intrapleurally. Talc can be contaminated with asbestos, which is known to be associated with the development of mesothelioma. Although previous studies have found no increased incidence of mesothelioma in patients who received talc intrapleurally, the authors rightly point out that the number of patients included in the studies was small. I believe that the risk of mesothelioma from talc pleurodesis is very small since, to my knowledge, there is not even a case report of such an occurrence. Nevertheless, the fact that the possibility exists provides another reason to not use talc for pleurodesis in nonmalignant conditions.

Dr. Sahn was given an opportunity to respond, but declined.

Richard W. Light

Vanderbilt University, Nashville, Tennessee

http://ajrccm.atsjournals.org/cgi/content/full/164/9/1741

17. **Talc (Intrapleural Route) Mayo Clinic**

US Brand Names

- Sclerosol Intrapleural

Description

Talc is sprayed through a tube into the area around the lungs. It is given to people who have breathing problems caused by a build up of fluid in this area**. Talc is used after the fluid has been drained out, to prevent the problem from returning**.

You may be familiar with talc used as an ingredient in dusting powders (talcum powder). The talc used for preventing fluid build up in the lungs is a special grade of talc that has been sterilized (made germ-free).

This medicine is to be given only by your doctor.

This product is available in the following dosage forms:

- Spray
- Powder

Before Using

In deciding to use a medicine, the risks of taking the medicine must be weighed against the good it will do. This is a decision you and your doctor will make.

http://www.mayoclinic.com/health/drug-information/DR601295

(What information was Don given? I doubt they told him about the very real risk for him of ARDS)

18. Talc for Pleurodesis?

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Richard W. Light, MD, FCCP (Nashville, TN).

Dr. Light is Director of the Pulmonary Disease Program, Saint Thomas Hospital.

Correspondence to: Richard W. Light, MD, FCCP, Director of Pulmonary Disease Program, Saint Thomas Hospital, 4220 Harding Rd, Nashville, TN; e-mail: RLIGHT98@yahoo.com

At the present time, talc is the agent for pleurodesis that is preferred by the majority of chest physicians in the United States and England. The reason for this preference is that talc, administered either by an aerosol (insufflation) or in a suspension (slurry), is effective, inexpensive, widely available, and associated with minimal side effects in most reports.

Concerns, however, remain about the safety of talc. The primary worry is the observation that ARDS can develop after its intrapleural administration. There are least at 42 cases of ARDS following intrapleural talc administration in the literature, 24 following the use of talc slurry and the remaining 18 following talc insufflation.[1 2 3 4 5 6 7 8 9 10] In some cases, the patients presented with respiratory failure and required

mechanical ventilation. Eleven of the patients died.[1 4 6 8 9 10] The reports of this complication seem to be increasing recently. In one recent article from New Zealand, Brant and Eaton[10] reviewed their experience with 33 pleurodesis procedures in 29 patients. They reported that major complications (*ie*, hypoxemia and hypotension) occurred in seven patients and that two of the patients died.[10] In another recent report, Scalzetti[11] reported that 16% of 108 patients undergoing pleurodesis developed a transient interstitial process in the lung ipsilateral to the treated pleural space.

What is talc? Talc is a pulverized, natural, foliated, hydrated magnesium silicate that has the approximate chemical formula of $Mg_3(Si_2O_5)_2(OH)_2$.[12] There are many talc deposits scattered throughout the world, and every talc deposit is unique with regard to both chemistry and morphology. In general, the companies that produce the talc that is used for pleurodesis do not know the origin of their talc. There are variable amounts of calcium, aluminum, and iron present in different talc preparations. Non-talc minerals associated with commercial talc vary from deposit to deposit and may include calcite, magnesite, dolomite, chlorite, serpentine, quartz, and others. Talc is processed by being passed through mesh to eliminate the larger talc particles. Accordingly, the mesh size sets the upper limit for the size of the talc particles in the final preparation.

The mechanism responsible for ARDS following intrapleural talc administration is unknown. The incidence of ARDS following intrapleural talc administration has varied widely from study to study. For example, at one extreme in Seattle, Rehse and coworkers[5] retrospectively reviewed their experience of 89 talc pleurodesis procedures in 78 patients and reported that 9% of their patients developed ARDS requiring mechanical ventilation. At the other extreme, Cardillo and associates[13] recently reported in Italy that there were no cases of ARDS in 611 patients who received 5 g insufflated talc intrapleurally. It has been hypothesized that the onset of ARDS following talc administration is dose-dependent, occurring in patients receiving > 5 g.[14 15] However, this hypothesis is probably wrong since de Campos and coworkers[9] have reported that acute respiratory failure developed in 7 of 550 patients (1.3%) who received only 2 g insufflated talc for either recurrent pleural effusion or pneumothorax. Four of these seven patients died of respiratory failure.

Another hypothesis is that the acute pneumonitis is due to the systemic absorption of talc with the subsequent elaboration of inflammatory mediators. Support for this hypothesis is provided by studies in both humans and animals. In the four cases reported by de Campos and coworkers[9] and in the case reported by Rinaldo and associates,[1] there were large quantities of talc in the BAL fluid of patients who developed ARDS following talc pleurodesis. Moreover, at the autopsy of one patient who died from ARDS, talc particles were present in almost every organ, including the ipsilateral and contralateral lung, brain, liver, kidney, heart, and skeletal muscle.[9] After the intrapleural administration of talc in rabbits, talc particles were detected in 17% of the mediastinal ganglia, 17% of the kidney specimens, and the 49% of the

splenic specimens.[16] Talc particles were detected in every organ of 40 rats that were killed 24 and 48 h after the talc was administered intrapleurally.[17]

If the systemic absorption of talc particles is responsible for the acute pneumonitis, then a reasonable subhypothesis is that talc preparations with smaller median sizes would be more likely to be absorbed and, therefore, would be more likely to produce ARDS. Indeed, we have shown previously that the mean diameter of the talc particles in eight different talc preparations varied from 10.8 to 33.6 µm.[18] Interestingly, talc preparations from the United States, the country with the highest incidence of ARDS following talc administration, had the smallest mean diameter. It should be noted that in sheep the mean diameter of the stomata, which are the openings to the lymphatics in the pleural cavity, are 8 to 10 µm.[19]

The article by Fraticelli and workers in this issue of *CHEST* (see page 1737) examined whether there was systemic dissemination of talc after the intrapleural administration of talc with a median particle size of 33.6 µm and a mean particle size of 31.3 µm. After a relatively large dose of this talc was injected intrapleurally into rats, talc particles were found in only 4 of 198 samples of the right lung, brain, liver, spleen, kidneys, and blood when talc was searched for in the entire organ. However, it is interesting that 75 particles were found in the liver of one rat. The authors hypothesized that these particles were due to contamination of the liver by other talc-containing tissue since the size of the talc particles was similar to that from the intrapleurally injected calibrated talc. Alternatively, the talc could have been absorbed. It is possible that interindividual variation in talc absorption might explain the sporadic occurrence of ARDS after intrapleural talc.

Fraticelli and coworkers conclude that the lack of the systemic dispersion of talc particles in their study is probably due to the size of their talc particles, which was larger than sizes in most talc preparations. However, definite proof for this conclusion would require the demonstration of the significant systemic distribution of talc particles after talc particles with a smaller median diameter were injected intrapleurally. It should be noted that 20% of their talc particles had a diameter < 10 µm. If the size of the particle was the only factor governing its systemic distribution, then one would expect a few small particles to be found in nearly every organ.

Another possible mechanism relating the size of the talc particle to the development of ARDS is that talc preparations with smaller median particle size would lead to the generation of more cytokines in the pleural space and the systemic absorption of these cytokines could lead to ARDS. Nevertheless, it should be noted that the evidence is far from conclusive that the occurrence of ARDS is related to the median size of the talc particles. Other possible mechanisms are contaminants of the talc preparations, such as endotoxin, or other organic or inorganic materials.

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 is dirt!! Our studies in rabbits and sheep have demonstrated that transforming growth factor (TGF)-ß induces a pleurodesis that is superior to that induced by talc, doxycycline, or bleomycin and that occurs faster.[20] [21] [22] It appears that TGF-ß induces the pleurodesis by stimulating the mesothelial cells to produce collagen and does not require that the pleural surface be injured as it is with talc or doxycycline. Inflammatory indexes in the pleural fluid after the intrapleural administration of TGF-ß are much lower than those after doxycycline or talc administration.[20] I would guess that in the future TGF-ß or some similar cytokine will become the agent of choice for pleurodesis. However, such a cytokine is likely to be expensive, and in underdeveloped countries a less expensive agent is desirable. Such an agent may prove to be silver nitrate, which at least in animals is more effective than talc,[23] [24] and in a preliminary report was effective in humans.[25] I believe that the use of talc will diminish due primarily to the fact that ARDS occurs following its administration and that the many sources of talc make the standardization of talc preparations very difficult.

Footnotes

Supported in part by The Saint Thomas Foundation, Nashville, TN.

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http://www.chestjournal.org/cgi/content/full/122/5/1506

19. The undiagnosed pleural effusion.

Light RW.

Vanderbilt University, T-1218 Medical Center North, Nashville, TN 37232-2659, USA. rlight98@yahoo.com

The most common causes for undiagnosed transudative effusions are congestive heart failure and hepatic hydrothorax. Pleural fluid N terminal pro-brain natriuretic peptide levels higher than 1500 pg/mL are virtually diagnostic of congestive heart failure. The most common causes for undiagnosed exudative pleural effusions are malignancy, pulmonary embolism, and tuberculosis. Clinical characteristics of patients with a malignant pleural effusion are symptoms for more than 1 month, absence of fever, blood-tinged pleural fluid, and CT findings suggestive of malignancy. Thoracoscopy is useful to establish the diagnosis of malignancy and tuberculosis.

PMID: 16716820 [PubMed - indexed for MEDLINE]

http://www.ncbi.nlm.nih.gov/sites/entrez?Db=pubmed&Cmd=ShowDetailView&TermToSearch=16716820&ordinalpos=4&itool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_RVDocSum

T Mackay
"Craggy Island"
43 Willow Crescent - Fembank Crk
Port Macquarie NSW 2444

Document C – Intensive Care at Royal North Shore Hospital from 4am 15th April 2007 till 17th May 2007

Don was in Intensive Care (ICU) from 15th of April 2007 about 4am till the afternoon 17th May 2007, when he was "discharged" on a ventilator being told that 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 they would work towards getting him home and as Don knew he was dying and had a horror of dying in RNSH he took the offer. A disturbing incident happened on this last day, which I will address when I get to the end of this time. During this 5-week time and especially on that dreadful last day I have spoken with our daughters, and sisters and it was as if we were all just moving through the motions sort of in a state of shock… such that it all felt unreal and surreal.

Some things, issues which happened especially on those last days are just starting to gel for us.

The atmosphere in our part of ICU on those days was of total chaos and a shifting sea of faces, with no nametags seemed almost like a sensory assault at the time.

I will make the point there that the reason I am including the time in ICU is because 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 die painfully from Cancer over a three month period, and it was graphic and bad but this was different… it was like a process and the process was much more important than the person suffering. There was little compassion shown to my brave husband.

He would not have ended up in ICU at al if he had had, as Dr   from the Spinal outreach Team expected, a simple lung drain and biopsies. She spoke at some length bout this to me soon after Don died, but the next time I spoke to her she had closed up and was also slightly defensive.

There is not one bit of doubt what caused Don's Respiratory Arrest and Acute Respiratory Distress Syndrome. Most of the ICU Doctors and Respiratory Doctors mention this in their notes. When I asked and asked them over the weeks not one of them would tell me the truth. Their notes are damming as to the cause. I thought legally they had to offer full disclosure to patients and if needed as it was the next of kin. Not in RNSH.

I am not sure how to structure this, as there are so many threads. What I aim to show here is the dreadful prolonged and cruel suffering Don experienced in the time above when he was in ICU. Much of this suffering could have been alleviated with better care and understanding, but the point is Don should never have been in ICU at all. If treated for his rea cumulated Pleural Effusion (not recurrent) he should have had simple lung drainage done, biopsies and when the lung was empty have been sent home.

It's a strange thing but what I feel is that these weeks were so shocking to watch (how much more so for Don) so awful that I had trouble remembering detail. It was as if it was just one long continuous day, which never ended; a day full of filth, cruelty and the pain of watching my lovely husband suffer more than I thought anyone could.

Our nephew Rod summed it up in one when in a recent email he described his impressions of ICU and Don's treatment and 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 RNSH approx 10.00pm Sunday night, this I believe would have been the 15/4/07, 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 Dons bed I had 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 Gidday 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 was the nurses one man (this is in ICU!) who could hardly speak English not one was helpful in explaining Dons well-being. The doctors, well they seemed non-existent, apart from one blonde 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 and comfort Don or explain what was going on with him."

Then 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 those "conferences" were a joke. We were not told when Don developed MRSA… I had to find him in the other ward. I was not told when that MRSA and Klebsiella Pneumoniae went to his lungs till about 4 days later when a nurse happened to mention it.

There were many times and incidences too numerous to mention when I was kept uninformed, and Don who could actually hear was just bypassed big time.

It was never explained to us the reasons for his extreme agitation. There was a certain amount of juggling about with his Methadone and Ativan, which would not have helped, but we were not told about that either. I will talk about this later.

All the time Don was in ICU even though I asked and asked I was never told the cause for his original Respiratory Arrest in Spinal Ward, and never told what the reason was that he was unable to come off the ventilator and had to be reintubated every time (about 4/5 times - have to check the exact number –

A good quarter of ICU notes, doctors and nurses are illegible, which is dangerous as a day or two after being written it would be impossible for staff to really get the full gist of what has happened and what had been written. This just added to the lack of continuity – will mention that later.

Now I have read their notes, those notes which could be read, and it is clearly evident that the doctors and nurses, and most importantly the respiratory Doctors knew exactly why Don had the original respiratory arrest and continued to have to stay on the ventilator till finally he was so diseased, so septic with their infections, full of fluid, lungs full of hospital infections he was "discharged" to die…he counts as a discharge - not a death.

Over and over in the notes they say that his respiratory arrest followed a failed pleurodesis or words to that effect and that he had developed ARDS (Acute respiratory distress syndrome) which is a known side effect of inflammatory reaction to the Talc used in pleurodesis.

They all knew. When I asked one of the respiratory doctors a tall dark man, if the Pleurodesis may have caused my husband's condition, he became aggressive in reply 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 this and if it were his wife or child in here like this how would he feel. Later he came back. He said that he was sorry I felt that way. Not an apology.

I thought it was a legal requirement that Doctors fully inform people 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.

They only included us when they wanted a signature on paper, or if we demanded to know so often… then they would call one of their damn conferences as if they were doing us a favour. For Gods sake this was Intensive care. Just having their loved ones in there shattered relatives. One young man said to me – he was in tears in the waiting room – he said that when you try to get information of them about your relative "they act as if you are trying to steal their lunch" this was spot on.

When I mentioned that there was a lack of continuity what I meant was that the Doctors seemed to all disappear after about a week and a new set would come on… as the notes were so poor and illegible mistakes in times and dates were made – Don went from having a driving accident in 1988 to having a driving accident in 1982, then they got it right, as a diving accident in 1982, but then the last doctor flipped it back to his being a Quad for only 15 years. This is just an example.

Not good enough for ICU in 2007.

I have also noticed that when I go through his notes I can't find his ward and bed changes noted in the notes. He had four position changes in ICU and yet looking at the labels and notes there seems to be no mention of when these happened and to which bed he was taken.

I am sure most staffing ICU had no idea that when Don was admitted he was "Alert and orientated" because by the time he had been stuffed about with so often, and because no one seemed to consider looking back at these notes… some of them expressed genuine surprise when they asked what he did and I told them that until this year he had directed his own company and successfully run and maintained a large commercial building which we had owned. Not that that should matter at all, but it showed me what other's attitudes were. If he hadn't been so physically disabled I doubt this would have been so

pronounced.

As mentioned above there was one nurse, who even the nurses couldn't understand. They told me this. I had asked them what on earth he was talking about and they thought it was funny because they couldn't understand him either. And he was looking after critically ill people who can die at any time.

You will note when I go through the days that almost without exception all nurses mention that Don was agitated or extremely agitated. The cause was never explained as stated. To understand how this affected him, you have to understand that as a C5/C6 Quadriplegic, when he is up in his chair he has a little arm movement, no hand movement and little strength… but the problem for Don had always been that when confined to bed, his arms lost their direction and were even weaker.

I would go in and almost everyday and see Don's arms tied to the bed and he would be constantly pulling on those 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 and often be daily. He was there for 5 weeks. It was awful to watch.

I even had to tie his arms down on the really bad days and always when I left his bedside as he would get his hands all tangled up in the ventilation tube and I know many times he tried to pull it out. He did manage to bite through the pilot tube twice I think and had to be reintubated. I hated tying his arms down. I knew what he was doing 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.

I believe also that he wanted those tubes out. Full stop – knowing the consequences. He had asked me some months before that if ever he was on a ventilator I was to make sure he was taken off…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 damage that Pleurodesis did to his lungs. I know, not believe, but I know he knew that and that he had made his decision and wanted it out.

I know that some of them knew what he was doing also.

Also the 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. There were weeks of this. It was horrible for him and for me and those who visited.

Much of the time the tube was in his mouth and tied around the back of his head to hold

it in position. The edges of his mouth were raw and sore at times and the skin of his mouth was all sloughing away from I believe the Candida which was right throughout his digestive system, from the very strong antibiotics he was on.

The only tooth left in the front of his mouth (Don had false teeth mainly) was knocked off and left in a sharp dagger in the front of his mouth. He lacerated his lips and fingers from this razor sharp and rotten tooth.

His body was so swollen at times it was horrible to see. The scrotum was stretched so tight with excess fluid it had to have been causing discomfort. Don's reaction to unrelieved pain was Autonomic Dysreflexia and one BP I noticed was 214 over 110, which for a Quad is shocking as they sit usually on 80/50. Don felt intense pain from internal organs and with all the swelling he had to be suffering.

His lungs both ended up with fluid in them (he only had a moderate right sided pleural effusion when he left Port Macquarie)…not just fluid, they also were full of infection, which was bloody tinged from the Klebsiella Pneumoniae and the MRSA.

Don's treatment, or disaster which was the tip of the iceberg which I have only touched upon up till now was a horror story.

Not one bit of this should have happened if he had received the right treatment when he came to RNSH. I am not allowed I guess to say that I feel they murdered him, that would imply intent, but I do feel that what they did to him was manslaughter with extreme lack of care and cruelty.

ICU is just a dirty chaotic mess. Unbelievable for a hospital in 2007 in Sydney Australia but we all experienced that…Don would not have been there but for Dr doing the Pleurodesis on him has his desperate condition worsened by this state of chaos.

Early days in ICU.

Firstly and to finish up with Ward 7D Spinal Unit, I find it disturbing to find that amongst ICU's notes are the notes written up by the Spinal Nurse for the whole time when Don was finally being observed that something was going terribly wrong. These notes as mentioned were written up retrospectively and are sparse on times… put them along the observation sheet which is not even dated 15th and it is clear Don was not attended to until it was too late. It is odd to read on these notes that Don's SATs were down to 83% but that this figure is not written up on the Obs.

Also I must note here that although I did ask for all Don's notes, the "Flow Charts" of observations were excluded. I rang about this when I realised and Medical records told me they did not have the facility to copy these ICU Flow charts, as they were quite long. We may need to obtain copies of these at a later date.

15/4/07 early
I just can't make out most of the notes except that there was a further mistake made about the cause and date of Don's original accident. These sorts of mistakes had to be caused by illegible hand written notes. These original medical notes can not be read, even though there is some medical shorthand, most of it is just scribble.

At the time all these notes were being written up I was in the waiting room. I had not been able to see Don and was sick with worry as nothing was explained to me about what had happened, apart from a brief sentence about the respiratory Arrest. Melissa arrived but we were no allowed to go in to see Don till a couple of hours had passed.

I saw Dr   briefly, very early that morning, and believe that was the last time I saw his admitting specialist, but was made none the wiser as to cause of what had happened, even though at 7 am one of his team Dr   (Cardiothoracic) **wrote in the notes,** "Events noted. Respiratory Failure with lo (I think this means with) inflammatory markers. ? (Query) talc reaction" can't read the rest. This is the same Dr   who had earlier seen Don in Spinal and said eh/she was "unconcerned".

This "Unconcerned" attitude by Cardio Thoracic, needs to be seriously questioned as at the time Dr   saw Don I could see clearly he was in serious trouble, but I just did not know what it was. I believe I should have been told what this doctor suspected or knew and should have been informed from then on every time I asked... I was to be kept in ignorance apart from my own research and that of my daughters and sister. We found out ourselves what caused it but even then no one would admit it to us...but there it is over and over in the notes.

They keep mentioning "Recurrent" Pleural Effusion. For us this is a term which was incorrect, but once on his records it became reality; and was the beginning of the tragedy, which unfolded.

On the "Record of Medical Emergency Event" his + + agitation is noted. It had been noted for days before by me and passed onto nurses and Doctor. It was I now know because of the build up of CO_2 in his system. They should have known this all of them. There are no excuses for this negligence. They ignored all my warnings and what was clearly before their eyes and for Dr   to say he/she was "Unconcerned" is

unforgivable.

He may not have proceeded all the way to Respiratory Arrest and subsequent ARDS.

He was terrified and they treated him like an idiot.

On this day in ICU Don had to have his arms restrained, a situation that was to last for 5 weeks. It was distressing for him and for us. There were a few reasons why his arms were flailing about as they were.

He was still agitated and on a fair amount of medication, and because he was a Quad even in his sleep his arms would draw up underneath his sleep as he relaxed. This movement was involuntary in sleep, but was more extreme with medication and agitation. His hands would get entangled amongst the tubes with the very real danger he would extubate himself.

Also another reason which still causes me tears and a type of guilt. Don had said to me recently that if ever he had to go on a ventilator, I was to ensure that he was let go, taken off. For the five weeks he was in ICU he was unable to communicate much at all apart from nodding and shaking his head as the tubes 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 horses bit and tightly round the back of his neck.

The area at the corners of his mouth became very sore and was cared for or not depending which nurse was on. Sometimes I would ask them to loosen it off because it was cruelly biting into his face, and it was distressing him mostly and us.

I think, but more than that I know that he genuinely wanted those tubes out. I believe he wanted to be let go even at this early stage. He knew, I knew that any major lung injury, or even a decent cold would be fatal for him. I know he knew what the outcome would be finally and as painful as this is to express my full thought is that in the days after he should have been given this.

I was in the awful situation of loving him deeply, of maybe holding out a small sliver of hope they might be able to fix up the damage they had done to him… Their explanations were so obscure I never felt like I was getting any straight answers on any thing.

I know that Don, much more than me, but that Don and I were is a strange sort of shock, and it was as if will had been taken away. I just sort of felt pulled from whichever "expert" was at his bedside, all of them seemed to be telling different things.

He 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 be for at this time.

It is curious to note that once Don was told that he would be coming home, his agitation dropped and his arms were calm and he was peaceful and very lucid. I believe that this was a combination of them stopping many meds (unsure) and the fact that he was achieving his aim. He wanted to come home and if that meant dying he was happy. It disturbs me that I feel like I failed him in his wishes. If he had not been so disabled, I but healthy I would have had no qualms about asking that his wishes re ventilation be respected. As it was I could not even ask. People would have no idea of the deep and real love between us; the companionship we had developed in the past 35 years was all for both of us. We were happy. Were I to suggest talking with Don in some manner in those early days re taking away the ventilator, human nature being what it is, there would have been suspicion of my motives. The general population has no idea of the degree of love there is between people in our situation.

So I said nothing and hoped. And all those weeks of Don's infection filled, suffering not once in that time did he show me anything but love and patience, and he was more caring for my welfare than that of 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.

With his arms tied and his mouth gagged and tied, and with all that was going on Don was also very frustrated and it always gave me a small pleasure to untie his hands while I was with him… Our daughter Melissa said at her Father's Funeral, "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."

I came to notice that with some nurses he was treated much worse. In ICU some of the nurses were the beat on the planet. I will never know their names, as there seemed to be no nametags and you forget after a while, because there were so many different ones. Its well-known Don did not suffer fools gladly. I was amused as was Don at how many nurses wondered that he could not move his legs…most people know what a Quadriplegic is. There were nurses who could not be understood, as their grasp of English was so bad. There were nurses who were patronising and once they had it in their heads that he was a Quad and "agitated" he also must be stupid. Their mistake, but he suffered for that. We had a private joke about those sorts of nurses, the ones who

spoke loudly over and around you to other nurses and weren't watching what they were doing or noticing the patient's discomfort…they were the "Bush Pig" nurses. Don had a wicked sense of humour and was a wonderful mimic of people. He was a very bright person and a good money manager; he was very funny and we laughed often, even when he was ill.

Still on the first day – They say he is now + + + agitated and pupils unequal and even intubated he was 45-65 breaths per minute. This alone would have been dreadfully uncomfortable and distressing…

NB here I am unsure of all the meds he was on as the charts are hard for me to understand. Even in Spinal I had to remind them to give him his normal meds, which cannot be, stopped cold turkey. He was taking heavy-duty painkillers and it seemed to me that even in ICU the drugs were shuffled about a lot… I would need someone who can follow this to look at this area.

I have don's normal med list, which he made, and kept on his computer should he have to go to hospital in a hurry. I will reproduce this at the bottom of this document. I believe that there were multiple reasons for his agitation and for the fact that on and off in ICU he seemed to be in a bit of a hallucinatory sort of state. If his Physeptone and Ativan were stopped and not started again, he would have severe side effects and major withdrawals I know that this was ordered at some time by Dr Low, but unsure of what other protocol they followed.

Rest of ICU – It is hard to write up a day by day account of his time in ICU as the five weeks seemed to be just an awful series of days where I even lost track of the name of the day of the week at times. Many days were so terrible that I recall often not "feeling" just doing and my face was often feeling numb and tingly.

I am not sure when Don's last front tooth was knocked out but had to have been 15th because he bit through the pilot tube of the cuff of the Ventilator tube at about 11pm 16/4, and was left extubated, as they had planned to try this the next day anyway. There are a few reasons why he did this I feel.

1. Extreme Agitation and tube intolerance
2. Pain from the rotten tooth and from its being a sharp spike in the front of his mouth
3. He wanted the tube out to die.

Or a combination of all three.

I signed the "NICE" Study to do with Insulin and hoped that this might give Don a

better chance…I was told it might. I hope it did not make things worse.

It was noted that after extubation Don was confused and disorientated. What and why was this happening? This was never explained even though we asked and asked. It just doesn't happen for nothing.

It was about this time that Dr mentioned that if Don was able to remain extubated he would be going back to Spinal Ward 7D. He thrashed his head from side to side and pulled at his arms so hard over and over that it had to be hurting him. He was more terrified of going back to Spinal than what he was of staying in ICU – I believe no one will ever know the full story of what happened to him in there. I have never seen my husband so scared.

During these days, our daughter Melissa, my sister Veronica, Don's nephew Rod and a friend Neil visited and all would have seen what I saw.

The 17th was a dreadful day as I watched Don go through exactly the same symptoms I had seen in spinal. His breaths were coming faster and he was not making sense much. He had been moved from his original spot in this ward to another spot because MRSA had been discovered there. Of course Don was going to catch it, and others.

This day they had Don on a mask with prongs. Unfortunate again as he mouth breathed…but they did what they did as usual. Alison was able to have the last real conversation she ever was to have that afternoon. He told her many times how much he loved her and kept repeating that when he bit down on the tube it tasted "Awful" he repeated this many times and they talked for some time. Alison said he was a bit muddled.

Physio began to get up small amount of secretions, never a good sign, as Don had not had this when he came to hospital.

Then he had to be reintubated because he was again heading toward Respiratory arrest…this having to be reintubated was a disaster for Don and had an ominous meaning long term. Yet when this happened his SAO2 was 100% and the instruments showed nothing as happened before. I had said to one doctor, "They have to stop looking at the instruments and look at Don – he is really struggling"

Now they see a moderate left lung effusion. The left lung had been totally free of fluids…none of this was explained… it just all happened around us.

The nurse noted just before reintubation that "patient initially alert and orientated responding appropriately to time place and person. Slowly deteriorating neurologically, increasingly agitated, disorientated to time and place, unresponsive after 11.50 SATs at 93-99%"

So unresponsive again…another arrest basically. How could ICU let this get to this stage? They were with him trying to reinsert an arterial line. We had been sent out, terribly worried. How do they let this happen in ICU????

Alison and Andrew visited from Melbourne on 18th/4… Nursing mentions thick secretions and also Physio mentions creamy thick blood stained secretions. More bad news, and none of this need ever have happened. He had almost another 5 weeks of this to go.

I rang that night at 10pm and the nurse told me about the left effusion draw that was to happen tomorrow. I expressed my disappointment at not being told. She said Docs only made decision at 21.00 but the notes show 18.50pm for this and I was always contactable and would have in fact only have begun to leave for the night at that time as usual.

Notes 19/4 Physio, most of nursing and Doctors notes are illegible…strange how they can all read each other's writing or can they? Alison typed up some bits at this time she said, "Thursday 19th April: Was aware in morning after a tooth brush from the nurse. He was nodding and smiling at Lissy and I and mum and I. 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 Dr. Delaney with Veronica, mum Melissa and I, it was uninformative and although we asked he kept saying he had no answers."

Don had a bronchoscopy 19/4. I can't even recall anything about this event. May have been told - may not but if it happened while I was there I would have been aware. Unsure as to results, just as I was unsure about just about everything.

Alison mentions this in passing but when we did have that conference with Dr
he basically asked us did we have any questions, and when we asked him what was going on he said he had no answers. So Alison said to him "What do you know?" He replied "Thats a good question", we were really trying to find out what had caused Don's respiratory arrest and failure to come of the ventilator, which was known according to notes made by Cardio Thoracic

As he wrote in his notes a few days later what he suspected 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 " ?? Can't read" 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 ++ (can't read), have reintubated him". I have to thank Dr. for ensuring that these comments could not be missed amongst the notes by marking them so prominently, but I wish he would have told us what he suspected caused the respiratory failure and failure to be able to be extubated. We suspected the same but no one ever really explained on a medical level what had happened. Again we had to do our own research. We are supposed to be kept informed fully of everything.

The medical notes by Drs and need to be read and understood by a doctor but they mention right lung exudate fluid and left lung transudate fluid... only today 10/9/07 have I begun to understand what these mean, because I was never told, "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)."

Their notes also have "? Talc reaction" and they still after all their testing have found no cause for the original effusion. They never did even after 5 weeks.

They note, "Disordered breathing" of course it would be disordered...knowing what we know now and knowing 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 knew this why on earth it him up in his wheelchair in Spinal when he was having visible trouble breathing. Again there seems to be a stupid lack of continuity and connection in their understanding of Quad breathing. Mentions see Consult sheet ad that there was no pre OP ABG. (what does this mean?)

CT CONSULT SHEET

This sheet needs to be read, can't reproduce it here in entirety. Some points made by Cardio Thoracic - they have him down as a Motor Vehicle accident 1982. Wrong. Also they list likely "asbestos exposure...most working men were exposed to this, he was not high risk.. They are wrong about when he stoped smoking, not 15 years ago 20 years ago.

Dr says he had Dyspnoea since 2005, when in fact it was only really around late 2006 when we noticed it. (They make so many mistakes.) He also says "Post Op confusion" I mentioned this to them in the two days before his arrest and no one took any serious notice till he was just before arrest. Dr. was "unconcerned". Dr then goes on to say, " I suspect he has had acute lung injury (unsure of symbol could be following...or as result of needs to be interpreted) pleurodesis with (upwards point arrow) effusions as a result. With his C5C6 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... (Runs off the page).... continues in main progress notes... (And later it was he who slogged it out denying the cause of Don's condition when I asked him in the last ward Don was in)

It was on 20th April that Dr (resp) said, "I am happy to consult and be involved but I feel that once ICU issues have resolved he should be a joint admission under spinal"

Spinal was never to become involved in Don's care although this was requested a few more times a comment was made by Spinal that they couldn't see that any purpose would be served by their becoming involved...words to that effect... Spinal should have been involved from the moment Don came to the hospital... that's why he came to RNSH ... because of the Spinal unit, or the remains of one. Under Joint admission with Cardio Thoracic and Spinal in the very beginning, Don may not have had that Pleurodesis so quickly, as the known respiratory reserves of Spinal patients may have been taken into account... maybe not. I will never know.

ICU from 20/4 on

The physio now reports "blood stained sputum"

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been involved from the moment Don came to the hospital... that's why he came to RNSH ... because of the Spinal unit, or the remains of one. Under Joint admission with Cardio Thoracic and Spinal in the very beginning, Don may not have had that Pleurodesis so quickly, as the known respiratory reserves of Spinal patients may have been taken into account... maybe not. I will never know.

And so the dreadful days began to all merge into one another. One day as bad if not worse than the rest.

I read the nursing notes 21/4 where the nurse says "Family aware of patient's condition and '???" in ICU". They may have assumed such because we were in front of him and seeing his suffering. We only knew what we saw and found out. Very little information was offered up and the communication was deplorable. All I ever seemed to get was that they hadn't found any cause for the original pleural effusion (we all knew what caused the huge amount now in the left lung...) At this stage they knew about the side effects of failed pleurodesis, and ARDS and all of that but I can not recall once being told any of this. Even if they suspected we should have been told.

Then the 22nd. Don was extubated in the morning. My sister and a friend Neil and I were visiting all day. I have trouble reading the nursing notes for this day. This 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 what I was seeing was 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...seems to be the way to go in RNSH. Only the Physio has noted my concerns word for word. The mask Don was on finally was a whole face and head thin. I watched the poor bugger struggle and struggle panting faster and faster, his tongue started going in and out of his mouth 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 the eye contact we had was telling.

I became quite frantic as the afternoon drew on. His breaths got up to 50 per minute on the machine and then inexplicably the nurse on duty turned the display either away so we couldn't see it or off...my sister remembers it being turned off (she is a renal dialysis nurse of 25 years duration) she was as worried as I.

I saw Don begin to go into full respiratory arrest and told the nurse who came over and looked at his face inside the mask... which was so full of condensation, he was barely visible. His tongue was being forced out as far as it could go. She said, "I think he is trying to speak"

Then all hell broke loose... I think we may have called another nurse. Of course not one bit of this is noted in the notes. Why would it be? So much like so much which happened. They never wrote down their failures to act after being warned. This nurse notes that he is "essentially stable" but shortly after this says, "hallucinating now difficult to rouse"

I feel sick to my stomach when I reconsider this day and how Don was treated. It was not necessary that they put him through this frightening and dreadful experience yet again. They should have seen the fact he was not coping and reintubated on the first. It was becoming clear he was unable to come off the ventilator ad they should have watched him more closely and taken my experience seriously.

Of course we were just hustled out and told nothing much as usual. We all came back in after the emergency reintubation, and Don was worn out and disorientated yet again.

It is at this time Dr writes and double strikes the comments recorded above, and here "" Mr Mackay has deteriorated post extubation today. Again he has developed delirium and " ?? can't read" 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 ++ (can't read), have reintubated him". Don was down to 81 CO2 if I read the notes properly.

23/4 Dr from ICU notes in retrospect that Don's condition is "Type 2 respiratory failure (a medical symbol? could mean following/as a result of ?) Pleurodesis 12/4... likely deterioal (sic) of resp. reserve (? due to?) with poor reserve (?) quadriplegia after inflammatory react to pleurodesis ...requested spinal team input.... S/B Dr (spinal) don't think she would have anything now to offer to ? she will d/w Dr (respiratory physician)... **problem** doing okay on ventilator. Every time weaning is tried he retains CO2, gets confused and needs resp support. Pt's wife is very engaged in his care and has requested a detailed update..(runs off the page) "

Later on it is noted that Spinal don't think they have anything to offer here. So cardiothoracic is trying to get them involved, IU is trying to get them in involved and although Don was a C5/C6 Quad (complete Spinal are just not interested at all and never were from the beginning.

Dr said also "I have spoken with Mrs Mackay and sister and updated them. He is in trouble with respiratory failure...I have answered all their questions."

But we were never told about the inflammatory response to the pleurodesis which was now acknowledged.

We had asked Dr to allow Don to have IV Vit C at 15,000mgs. Many doctors report that at this level there is a greater chance of the patient's immune system doing better than it does without this level. We had had medical advice on this and on the amount and delivery which would not have been a problem as he was on IV anyway permanently. She would not allow this at this level even though the Pharmacist said it would not be a problem to deliver if the Doc okayed it. At this desperate point in Don's dying we are still angry that we could not force this issue. It may or may not have helped with Don's condition but nothing they did helped and the prognosis at this point was pretty hopeless. This attitude in medicine makes me sick. They rattled on about kidney stones etc.as if? But what are a few stones if the person survives? She allowed only 1,000 Vit C daily - orally which was just useless because of all the antibiotics he was on and the by now systemic Candida albicans which had subsequently invaded his digestive system he would not absorb much nutritionally via his stomach anyway. I did purchase some strong probiotics from a naturopath in a hope of fighting what I knew would happen to him once the antibiotics did their work, but that was also not allowed. At home daily Don in normal health took 3 to 4,000 mgs Vit C and a very strong probiotic daily and had done for years with no kidney stones or other ill effects. The Pharmacist also had not problem with this as long as the Doc okayed it.

We also mentioned a Cortisone (unsure) treatment for ARDS which is in the literature and which can turn it around in many cases... but there were reasons against this also which I would like to have explained.

We all knew Don's outlook was grim and I would like it explained to me why he was not given every chance at survival, but denied things which might have just given him a sliver of an edge or at least made his suffering less brutal. His suffering was brutal and if at this time I could think of a stronger word I would use it. But their treatment of him, and apart from an exceptional few nurses and Docs who forever have my thanks, their treatment of him made his suffering much worse.

This seemed a systemic problem.

The resident Medical officer reports neg results on many of the tests taken to see what was causing Don's original effusion. This stayed the same till he died.

Often through the weeks the nurses and physios especially reported that Don was "not

following commands"; generally on these days he was plus agitated and I could see the distress he was in. he appeared to be coming in and out of hallucinations at times as if he could see things we could not see but would just as suddenly snap back to himself. He knew this then and it was dreadful for a man like him who had always had so much mental control. The reasons for this have never and were never explained, but as previously mentioned he became totally lucid once all extra meds and treatments were stopped...this needs review, because it caused him distress and robbed him of so much time and us of him.

24/4 S/B Dr noted 3rd failed extubation mentioned 2/7 days ago and noted marginal resp reserve- diaphragm dependant and v week resp muscles which make wean from ventilator v difficult agree trach seems v likely. Suggest to relieve no mechanical impediments to respiration egg. residual R Pleural effusion. (cant read who wrote this)

But here is another issue along with Don's Quad breathing... "V weak resp muscles" he always had these and over the years they had become much weaker...another reason not to do the Pleurodesis.

So cardiothoracic is trying to get them involved, IU is trying to get them in involved and although Don was a C5/C6 Quad (complete Spinal are just not interested at all and never were from the beginning.

RMO NOTES 24/4notes in entirety as to me and after reading all the doctors previous comments about Inflammatory response to Talc Pleurodesis and Acute respiratory distress syndrome as a result (ARDS) the RMO now notes,
"Family members Sister in law and wife Therese Mackay, Cardiothoracic Registrar (who originally signed don up for the op after seeing him for a few minutes on the night he arrived at RNSH!) and - Family concerned about sudden deterioration is Donald's condition after pleurodesis, compared to his pre-admission state. They have investigated on the internet about VATS Pleurodesis and were (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 (this is when we mentioned the cortisone treatment recommended for ARDS).

It was explained by the registrar that the thought was that he had has an allergic reaction which was treated (please explain when and how this was treated) and that his current state is not likely to be related to the allergy itself.

It was also explained that as yet there is no known cause for the pleural effusions but they are still recurring despite the pleurodesis, and that for the moment his treatment is

symptomatic. They have requested that he could have some Vit C to improve his immune system and I explained that this would have to be cleared by Dr

In their research they also came up with a list of potential tests and whilst the majority of these have been done again I will d/w Dr

Although concerned they understand that until we know the cause of the effusions it is difficult to predict his response to treatment." Cant read signature 45725
End

Perhaps they should have thought of testing the original moderate pleural effusion **BEFORE** Dr. did the Pleurodesis, which buggered up the mechanism of his breathing and caused him to be in ICU dying, in the first case.

Dr should have drained the effusion, tested the biopsies and considered Don's ability to survive mucking about with his lungs. We were very unsatisfied with this so called conference, and aware of the attitude to our doing our own research. We were forced to do this, as no one was straight with us. Even here they are fudging about and making unclear statements, not having the guts to say 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, and Don's to be told exactly what all the Docs were writing in the progress notes, but instead we got little bits of information, which were well nigh useless. Everything we found out on the net even using one of Dr own letters was exactly what happened and the doctors notes in progress back this up.

Blood Bags given He was given blood 24/4 because of Haemoglobin levels dropping. He had a few bags of blood over the time and it was never really explained to us how and why he would need this much. I would like to know this. Around 10th May, near the end I was present when they were obviously really worried about him this way and a doctor and nurse actually force squeezed two bags of blood into Don as if it was an emergency. One of them squeezing the bag while the other attended to the connection... they changed positions with the second bag. I have no idea why this was happening. At this late stage, I don't even remember what I was thinking apart from trying to soften things for the girls and rub cream into Dons feet and arms so he would know me and how much I loved him. He would let me clean all the dead white skin from his mouth and put in the gel which soothed his raw mouth, and when I washed his face with a warm washer (only thick paper) he would relax for the moment and lock onto my eyes and I could sort of go into his world for a bit. I felt as if my heart was broken over and

over and don't remember what I did much the rest of the time, who I spoke to, how I interacted.

Somewhere around here he was moved into another bed in the same ward because of the MRSA they had in his area... but no mention on the notes.

24/4

DR mentions a loculated R Effusion...how did this happen? What did it mean for don ...never even mentioned this? I believe it meant that there was fluid trapped between the talc

By now almost every entry by nurses and physio mentions agitation. As mentioned previously this agitation wasn't just mild it was constant movement and fast and he went between this state and total sleep and exhaustion when his body just gave in. Again this extreme agitation has not been explained.

Again someone needs for the safety of those in ICU (the patients) to do something immediately about the fact a lot of the notes in ICU especially important here are illegible. This is a major issue for me, because with the lack of continuity of staff and docs, added to inability to easily read notes from the days before, this is dangerous.

25/4 The nursing notes have Don becoming agitated and throwing his arms about trying to pull out his Tubes.

Melissa and I were there when at 1.30pm he bit through the tube and as the air gushed out of his mouth when the balloon deflated he called to us to "Help me." possibly the last time we were to ever hear his real voice again. Melissa and I were again hustled out. I think Don wanted us to help him to die basically and that that was his choice... I don't know why we didn't press this at the time...but it was as if you were emotionally pushed about in and out...

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.

Back in with the tube.

26/4 the Nurse mentions that the NICE study was overridden at times because of low BSL?

Dr (Cardio Thoracic mention D/w with Dr ..so although we hadn't see Don's admitting specialist for some days he was obviously still in the hospital.

The right lung was being drained and the left one has remained in.

27/4 I read here that the "plan was to stop meds which could cause general fluid retention. Two of these meds were Lorazepam and Methadone both of which Don and been taking for many years. Lorazepam (Ativan) 3 tabs a day and Physeptone (methadone) at 3 and half tabs a day. I need someone to look at all the drug charts and see when this was done and was the methadone and Lorazepam replaced with similar drugs which would have covered the dreadful withdrawals Don would have suffered had these two been stopped suddenly without replacement.

Left and right lungs were being drained at this time.

DR discussed with DR Low (ICU that a course for r pleural effusion may not be identified, that ongoing resp failure related to resp muscle weakness, superimposed mechanical problems of pleural effusion agree? respiratory depressants.

When I look at the notes for the next few days they say that he was plus plus plus 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 and there seemed to be no explanation for this. I hope that the NICE study had nothing to do with this. Someone with medical skill may see something in the notes on medications, nutrition and other which taken together with other issues may explain not only this but why he was "haemo dynamically unstable at times". (29/4 They noted in his notes that 27th April but it was like this most of the time) that he was "grossly oedematous" Why was this please?

If it was fluid in his lungs at this stage, why were all these other quite serious things happening to him? There must have been reasons for all of this. Most of the times I had no idea, 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 etc. The fluid in his body, trunk, arms legs and especially his scrotum was unbelievable at times. He had always had extremely thin arms because of the Quadriplegia, but at times they were so fluidy you could leave fingerprints in his arms accidentally.

29th April The nursing notes written up at 17.20 are easy to read and are pretty typical of

the days he was enduring. His suffering was dreadful. It was unnecessary. With the right treatment Don should have been home and alive a few days after the "surgery" we believed he was having. There was still over 2 weeks of this to go and each day he was worse, his lungs were worse, and his suffering worse.

30/4/07 this was day 16 in ICU. His arms by now had been restrained for over 2 weeks and would be for another 2 and half weeks. He had been unable to talk to us for all this time, and we tried to communicate without eyes and his signals. The only communication device that as offered was a bit of paper with symbols like "Make up", "toilet" etc on it. This was laughable in ICE and Don was unable to point in a straight and controlled way because of his Quadriplegia anyway. He became extremely frustrated at this. I think that Spinal Input with Occupational therapists could have helped him here as they deal with high level Quads who need communication devices, but Spinal made it very clear he was not one of their responsibilities.

Again they have extubated him - at 10am. Almost straight away I could see he was in trouble as with the other times, I made sure they knew and this time at least. But not till 2.30pm. By this time he was breathing too fast, upset...very upset. Poor Don and poor me too. To have to watch these continual failed extubations and the suffering Don endured... they would leave it till it was dreadful to watch before they would reintubate. How much more dreadful it was for my lovely husband. He suffered so much, too much. All needlessly. None of this should have ever happened to him. We have the doctor's notes here DR "required reintubation. Progressive type II Resp failure."

I am now reading notes by a Dr 30th April. They spoke with me about the failed extubation, and here she says "She understands his breathing is related to infection/fluid/ alteration in lung mechanics" I understood what she said, but was not told what infection certainly not what I was to find out about a few days later, although they would have had an idea at this time what those infections were I would hazard a guess, going by what the nurse 5/5/07 told me. I understood what I was being told. I still maintain that none of this should have happened. It was the failed and unnecessary Pleurodesis, and subsequent neglect, which put Don in ICU. She mentioned the possibility of a trachea or just keeping him comfortable, and held out some hope for the trachea. I told her that Don had spoken to me about not wanting to be on a ventilator prior to RNSH. It was explained that the trachea would be a lot more comfortable for Don and that he may even be able to communicate once it was in. 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, 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.

The Isolation room
I am unsure when and what date Don was moved to the last ward, which was to be where he spent the rest of his life, another 2/3 weeks. I wasn't keeping notes at this stage... and can't find any reference to this at all in the notes. This little one bed room was dreadful. It was one of four pod type rooms - isolation (isolation - that was a joke as well)

When I found where Don had been moved to I was pretty downcast to see they had put him in one of four small rooms 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, Don was to spend the rest of his life basically in a room alternatively too dark for nurses to be sure of what they were doing (I would turn the lights off to give his eyes a break from the bright fluoro light above his head...there was no halfway with this light... it did not turn down). The whole environment in this room was as if it was cut off from the outside, and only sometimes could we see a small patch of sky and that when we would ask if the curtain next door could be pulled back a little. Thankfully we had no idea how long Don was to be in this room when we first came into it. I know in my heart that Don and I knew he would probably not get out of the mess alive and I know he did not want to die in RNSH, as we had talked about this only months before. He wanted to die at home, and to be able to stay there for quite some time afterwards. The thought of dying in this place had always been a worry for don, from the first time he went there in 1982.

Infection Control in Isolation ICU RNSH The infection control at RNSH is and has always been dreadful. The first time Don picked up MRSA was in 1982, and that then was the best Infection control got. In those days visitors, nurses and docs were issues with a total cover gown which covered all the areas on the arms and sides of the clothes. Each time Don went back we noticed it getting laxer. One time in 1994 he was opposite a man who had Hep C and some other highly contagious disease and the wards men/lifters would go from one patient to the other lifting and turning and many is the time I saw them and some nurses and docs "pretend" to was their hands as I waited outside in the corridor.

But in ICU, with MRSA, and all the other by now potentially deadly bugs threatening critically ill people all of us had to wear little disposable plastic aprons which only covered the same area that bib aprons cover. Arms, the sides of clothes were all exposed. Hands only were washed, but mostly the staff used a solution to do their hands in. These aprons were disposed of each time you went in and out, often they were thrown in the

general direction of the bin and many was the time they would sit there. I would put gloves on and try to sort the room out when I got there, and there were some nurses who kept the room in good order, but often when you came in it looked like a bomb had gone off in the room. The wards men would then come around and clean all this filth up off the floors, going from ward to ward in the same useless aprons we all were issued. They would then do the rounds of helping the nurses to lift and turn patients. It is not their fault but they would have to have spread the MRSA and other to many patients and wards in this way.

The same goes for the Doctors, nurses and relatives/visitors. The area covered by those silly little aprons was useless. For true infection control in such seriously ill people they should have had total cover. If they could do it in 1982, they can do it today.

The infection control in RNSH especially that I saw in ICU is a crime against the well being of the patients and it was getting these infections so soon after entering ICU that made Don's suffering so much worse. Melissa and I who visited most often came away from that place with in her case rashes which would not heal for some months, sore throats which would not go away for some months, large (20centpiece) lump under my upper arm which took months to disappear - this lump appeared quickly and was disgusting...it was full of pus and kept bursting and re filling and was about a month after Don died that it began to shrink. It seems to have disappeared for good but not until a few weeks back. Both of us are pretty healthy but have not felt really well since being in that place.

One day in there we were with Don (it was a Sunday) and I started to have a panic attack (I never get like this), and was amazed to see she was really struggling herself. When they came in to turn Don, we walked outside the room he was in and into the corridor. She said she felt a bit better already. So we went out into the open air for a short while and both totally recovered... it was the air in the room. I don't know what was going on in Don's little room but when we went back the same thing happened, but 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 his closed off portion of the hospital the oxygen mix was not adequate... I am not prone to panic attacks especially at this time, I was to numb to react to much at all. The nurses also commented on the stuffiness.

Amongst all this filth he was expected to fight the disastrous damage that the failed Pleurodesis had done to his lungs. If he had ever had any chance this dirty hospital lessened any chance he and others like him ever would have.

The nurses would say "But 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 RNSH 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 RNSH to hygiene, to accountability and to taking responsibility and I feel very 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.

Much worse for seriously ill patients.

Not told about MRSA and Klebsiella Pneumoniae lung infection On Saturday the 5th May I noticed that the Physios and the nurses when they iniated a cough through Don's tube, because his lungs were full of fluid were bringing up a thick pink horrible looking secretion. I asked the nurse what it was as I had never seen this before. She looked at me in a sort of surprise and then announced "Weren't you told that he has infections in his lungs now?"

I had been aware that there had grown MRSA at the site of his arterial line in his groin - 0nly because I had asked why he was moved beds... this information was never offered either.

I was shocked about what this nurse told me and asked her what they were. She then told me that Don had the dreadful infections of Multi resistant Staphylococcus Aureous (MRSA) and Klebscilia Pneumoniae in his lungs. This was a major disaster, on top of all the other major disasters. He had come into hospital from Port Macquarie (home and PMBH) infection free. With adequate hygiene and care this was not something that had to happen, but was directly caused by dirty practices in a dirty hospital.

I assumed that this must have just been found, so when I asked her how long had this been known, she went to the notes and said that they found out on 30 April and or 2nd May April some confusion here. In ICU in 2007 in Sydney Australia something as bad as this had happened in my husband's care and not one doctor thought to inform me, Don's wife. I was there every single day of the six weeks from 12 April till the day I left so Don could come home to die. I was there from about 8/9 every morning and not one person came and told me what was happening.

Again as with just about everything else I had to find out for myself. That day I felt such a degree of anger and disgust at the whole bloody hospital system it sickened me. Poor bloody Don was suffering so much already, tubes in his lungs which are never comfortable, but for the extended periods he had them in for would have been dreadful; so much fluid in his body (read the notes) that he would have been feeling extremely

uncomfortable from this - this fluid retention was never explained to me - Fluid in fluid out why the retention? I asked often about this but no one explained why this was happening. Tubes hanging out of just about every place they could hang, a body riddled with Candida Albicans (his mouth flaking away and sore, hair unwashed apart from one time in his stay in ICU...I would mop it with a warm washer to try and get the smell out of it. Now lungs so full of not only the transudate and exudate fluids in Right and left, but filling up with the infections caused by the hospital and its ridiculous attempts at hygiene.

1/5/07 Sepsis is mentioned in the notes. I know this is to do with infection, but am unsure as to if sepsis is a whole body thing or was it confined to the lungs. Of course 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 do know that if one has severe Candida Albicans in the digestive system it is unlikely that nutrition will ever be adequate. This is where the high potency probiotics would have at least helped in this instance. Another wrong turn.

I am also querying why Don needed 2 Units of blood and was never told why although I did ask. Why did he need so much? Even my sister who has nursed with Renal Dialysis in Brisbane was not impressed with their explanation for this state. I will need to ask her on this.
2/5/07
Nursing notes mention Don's unequal pupils. We noticed this a lot of times and once Melissa and I noticed that one pupil was elliptical for a time. We drew the nurses' attention to this and it was quite pronounced, 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" Not told about this.

Infection timeline after 30/4

30/4 Klebscilia Pneumoniae (KP (blood)); Pseudomonas Aurignosa (Urine); Candida Albicans (urine); MRSA (sputum) Candida Albicans (sputum) KP (sputum)
1/5 MRSA (Chest);
8/5 KP/MRSA resistant to all but 3 - sputum (from lungs)
12/5 KP(Blood); MRSA 2+ (swab Index finger); Kp+2 Sputum.

If Dr operation hadn't buggered up his lungs, then this sort of in infection in his lungs, he was never going to survive. They must have all known it was hopeless for a Quad to survive this.

At no time was I fully informed about all of this. I knew because I asked... but was not told anything I did not ask. I did not always know the right questions.

<u>Tracheotomy 3/5/07</u>
DR (Resp) mentions "phone call from ICU staff to 'sign take over sticker' Issues noted 1. Undiagnosed R exudative effusion" can't read the next of this bit ... 2. Transudative ongoing pleural effusions... 3.Klebsilla sepsis blood/line Timentin 4. +'d platelets 5 longstanding spinal injury 6 problematic autonomic Dysreflexia" and later on " We are happy to provide a consultative service re ventilation, or at best (?) shared care (with spinal) but I am <u>not</u> going to sign 'take over care' sticker.

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 really wanted and that was to come home and die, as he knew he was dying. But I knew he had a real horror of dying in RNSH especially. He hated that place from treatment in past years.

I find it so hard to read the notes. Some are really clear but some are illegible so am sort of patching together what they "say" and what I remember. I would like to see these notes translated clearly. ICU notes should be legible at least.

Alison has noted on this day "Tracheotomy (sic) put in and he is doing really well after the operation things look good. Later in the arvo he became really agitated, was agitated and awake all night" Poor Don. Poor kids. Just after the op, he responded so well and was so happy he came through okay as he was so ill, anything could have happened to him at any time...I knew this, so in a hopeful way, the girls were hopeful that this op might be the turnaround for him. I had a small sliver of hope but the practical side of me knew better. Don I feel at this time was just doing what he could do to get himself well enough to get home, and die there...if that makes sense. He was never stupid and always knew how he was better than the rest of us. But he couldn't communicate. This frustration along with all the dope he was on was partially some of the cause for agitation, but never explained the lot of it.

<u>4/5 Drs note "Day 20 admission post resp failure from VATS pleurodesis"</u> There it is again. No doubt at all about what put him in ICU.

Alison noted that he "was very tired all day and nor overly responsive". As mentioned he swung between this exhausted state to almost wild agitation and varying degrees in between. In the times he was calm, we would just often sit together and I would tuck my hand in under his ear. He would lean in on it for comfort. We comforted each other this

way often...this is something we did at home as Don had little feeling in other places. Even at the worst of times, and it doesn't get much worse, Don would look at me for a long time and I had the feeling that he was more concerned about me than he was about himself. I believe that he was unable to control a lot of the agitation and sometimes hallucinations, but that in some part of him he was sort of sailing till it was over.

There was a dignity in him, and in our family...the girls have it also which transcended all this shit. At times for the moment between all the shit, noise, filth and suffering it was as if we were surrounded by waves and waves of love.

As mentioned above it was only today that I was told by a nurse of the serious lung infections Don had developed...and only after asking why he had thick pink secretions from his lungs.

Dr's note "ARDS" in their notes... again I was never told about this. We discovered this term on the Internet which some of them seemed to think was hugely funny and humoured us. But the information we gleaned was more spot on than what we had ever been given, so that by the this time we all had a pretty good grasp of what had happened to Don and why. These notes have just confirmed this.

A nurse notes here that "patient was 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 and it was so hard to know the meaning of what he was trying to express.

At his time they were bring back an increase in his Physeptone (methadone) and Lorazepam for agitation.

Dr ⁻ mentions in issues " ARDS/pleural effusion leading to respiratory failure"

By now Don's left lung was draining quite substantial amounts of red coloured fluid daily. This lung had been clear when Don came to RNSH... so now Don had a left lung which would not stop producing fluid, a right lung which was beginning to reaccumulate fluid and both lungs full of bloody muck from the Klebscilia Pneumoniae and MRSA. They said he had Klebscilia Sepsis. His body was dreadfully swollen below tummy level; he was swinging between extreme agitation and total exhaustion and on and on.

Onwards

6/5 Now Blood stained plugs were coming up from Don's lungs He was not going to recover from this. Don and I both knew this and had done really if being honest, since he

began going downhill in Spinal. The rest of all of this was just a disaster. trying to patch up things as they happened, like putting the little Dutch boy putting a finger in the dyke.

Dr mentions that Sputum was still being produced +++.

There was no sign at all of Spinal Team's input. Some support they were. Spinal patients should be made aware of this, as spinal medicine is unique and needs are different. The other doctors recognised this. He should never have come into the hospital under a Cardio Thoracic doctor but Spinal.

7/5

Don began the "sprinting" today. The plan after the trachea was to try and train Don's lungs to kick in again by "sprinting" him. This meant that every hour between 8am and 8pm I believe he was to be taken off the ventilator which was attached to his trachea and attempt to breath by himself for 5 mins plus or until he needed a rest. The first day 7th I watched him do this it was done properly by the nurse and at the regular intervals instructed. She was an excellent nurse. Again I can't recall names as I can not recall ever seeing name tags on any of them. This made it very hard to remember who said what or who was who as there were so many over the period.

Dr notes 7/5 are very hard to read as were most of the doctor's notes. Three doctors whose names are illegible and hopefully what I translate is what they have written but they state, " Resp failure ARDS post Talc Pleurodesis.

This may sound trivial, but Don had entered hospital with a very long big toenail. I never cut Don's, as his circulation is so poor. The podiatrist who was to come to him at home never seemed to show up and we had more pressing concerns at that time. In hospital one of the nurses arranged for a podiatrist to come and get rid of this as it was getting caught on the sheets. I was dismayed when I watched this guy dig into Don's skin when he was cutting the nail. We had just wanted it 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. The podiatrist ordered daily dressings for 3 days with Iodine.

Some days and increasingly it was awful to listen to the noises from his lungs. When he indicated or when I considered it needed I would ask for the Physio and he always was more comfortable after that. He got to really appreciate what the Physios were doing...it eased things. If no Physio I would ask the nurse to initiate a cough through the tube, and

what came up was horrible.

In ICU each nurse only has one patient except at mealy breaks or on other occasions if a nurse has to get something. 17.45- Nurse notes "Air entry harsh breathing sounds on both lungs and wheezy all over"

I believe Don was dying at this time and everything being done was just extending it...but on we went.

7/7 Dr's notes "Type II respiratory failure post VATS Pleurodesis" I wonder had Dr and staff read these notes would they remember how glib he was just after Don's original respiratory arrest when he quickly stated that the Pleurodesis was not responsible. He could not have known that at the time and it needs investigation as to why he would make such a statement when all the other Doctors, even respiratory state over and over what caused the arrest and ARDS.

8/5

The nursing notes early on this day 4.15 make no sense to me. The nurse says Initially very agitated, trying to pull out tracheotomy and NG tube by hooking fingers in lines, **spitting** on nursing staff.... breakthrough Lorazepam given...and then later sleeping for long periods." In all 35 years I have known Don not once ever, in the early days when he had the odd beer or when very angry over something or whatever...in all those years he never spat at anyone. Never. For Don to spit on a woman or child that would be unthinkable. I do know when he tried to speak through the tube he would use his tongue and make a hard "T..T..T" sound But if he did spit on them I have to wish I knew the other side of what was happening. It is so very out of character. I will never know, but know enough not to take these notes at face value, as will be shown on the notes for the next nurse later this day.

This day had to be just about the worst day for Don especially and for Melissa and I. Our friends Neil and Renata also visited on this day and witnessed the dreadful nursing "care" he received this day. I arrived at the hospital about 8.30am. I assumed that Don had already begun the "Sprinting" breathing as ordered by the doctor…this should have begun at 8am. At 9am, when it was due again I queried to this nurse (Chris?) 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. I explained to her the importance of what they were trying to do and that it had to be done hourly to be effective.

She finally began at about 10.30 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 nurse pervious had taken note of what Don was experiencing.

This nurse's notes reflect nothing of the day we experienced. When I came into the room it looked like a bomb had gone off. There was garbage and gear everywhere and she seemed unable to regain order at anytime in the day. She spoke to Don in what I can only describe as a nasty fashion, which he was very aware of. Over explaining ad nauseum why she couldn't do certain things as if he was retarded or brain damaged…right into his face. She seemed much more comfortable outside his room doing notes or something. I spent much of the morning cleaning Don's room and face and reassuring him I was well aware of what the nurse was doing, or not doing.

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. I don't need to mention the lack of hygiene in the room, that goes without saying. On this day Melissa offered to stay with her dad for a couple of hours while I went over to Chatswood to buy a couple of suitable tops as I had not thought we would be down in Sydney this long. She said that as soon as I went Chris (?) showed her true colours and didn't even bother trying to hide her attitude.

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 especially 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 Melissa was quite upset and Don was extremely agitated. But and here is the rub, the Physio reports 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 would bite 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 the nurse clean his mouth or do anything to him he could avoid.

The doctor and Chris (nurse) had a lot of trouble trying to get Don's BP to go down and kept giving him Clonidine. This didn't shift the BP. I said to Chris, to use the Adalat liquid (USP), which we use at home and which always works. She wouldn't touch it. I

told her that the Pharmacist had approved it for use and finally after checking with the Doc it was allowed. I warned her not to give it to Don by putting her fingers inside his mouth to squeeze the capsule under his tongue and offered to do it myself but she wasn't having any of that. I told her he was biting hard on anything which went into his mouth and to be careful. Neil and Renata were there by then.

So she went ahead and put her fingers in his mouth to deliver the Adalat, and he bit down hard and hung on…but his eyes were not with it. She raced about the outside showing everyone and demanding blood testing and showing everyone and came back inside to demand that we say we saw what happened.

His BP came down straight away as I had known 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 tooth they had knocked out being rotten and sharp.

There was no more "sprinting" as the Doctors made the decision later that day he was not tolerating the training.

I didn't leave that evening until the new nurse came on shift and I was assured things would be better.

All this time from admission in ICU 15th April and on till the end Don's arms were restrained, and he was almost totally unable to communicate any wishes apart from Yes and No and rolling 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. It felt like "research" by this time. For Don this was unbelievably cruel. There was no way his lungs would ever work again and I only wish someone had had the compassion and guts to declare this back in April after the first few extubations failed.

8 and 9/5 Much of the Doctors notes I just can't read. If someone takes the time to try and read the notes I think this is an issue.

Another issue is it has not been explained to me why Don was so continually agitated and often having hallucinations, but yet in the last days after he was set for Palliative care he became very lucid and calm. Someone who knows needs to examine the medications. I know that 8/5 the day above, the nurse Chris had left the feeds off and the Insulin on and was told to turn on the feeds…things like this happened off and on but not notated.

9/5 Again he tried really hard to get the trachea out. I believe he had had enough and wanted it over.

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 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.

Before I go onto the last days some incidents need addressing…
There was a young woman in a room opposite to Don. She was about 32 and had brain damage from an accident of some sort. She had problems but could also be lucid at times. One of the nurses seemed to egg the others on a bit and I watched her mimic this woman as she called out from her room. One time there was a big laugh from these nurses, the one in particular and the young woman called out "I hear you out there laughing at me." The main nurse said, "We're laughing at something else out here, not you"… I should have said something to her relatives because it is disgusting for nurses to behave in this manner, especially in ICU in 2007.

Infection
Another query was that after she left that room another man came in. The room was "sealed" as he had something which was even worse than MRSA and Klebscialle… something they were really afraid would spread. Even so there were breaches of hygiene which would have allowed it to spread. It is unbelievable that someone so ill should be nursed alongside of other critically ill people.

I mentioned this because on Don's last day alive, just before his "discharge" my sister Jackie witnessed the nurses closing all the curtains to Don's room, even the one across the door. On this last day he was totally closed off. She also witnessed someone spray some substance right round four corners of the doorway out of Don's room.

What I would like to know was why this happened? What was the product sprayed? Why was Don's room kept so isolated? Was there some new or other infection we were not informed about?

11/5/07 Doctor ?'s notes (can't read name.)
"Day 25 ICU Type II Respiratory Failure Post VAT Pleurodesis ® for recurrent Pleural Effusion of Uncertain Aetiology. C5/ Quadriplegia Diving Accident 1982; Autonomic

Dysreflexia; Neurogenic Bladder; Chronic neuropathic pain; Minimal Respiratory reserve; Failed Extubation X 4; tracheostomy 03May…"

There is a part here, which I can't read… but may be relevant to his illness and suffering.

Dr (respiratory) notes
"Ongoing Ventilator dependence; grossly oedematous; hypoalbuminemia;" (we were never told about this either…it should have been explained);

I just can't read much more of his notes except where he adds " I continue to feel spinal should be (something) with our input (as joint care) "
(Spinal was just not interested.)

Physio When I read through the notes I must praise the Physios. On most occasions Don was more than happy to see them and to have Physio. Towards the end he actively indicated he desired extra as when Physio was done he got a temporary relief to the drowning which was happening in his lungs. The Physios were wonderful, professional and caring. I cannot praise them highly enough.

12/5 Don was extremely agitated early on on this day. He had a lot of pain on this day 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…this was visible and commonplace.

Now that I know he has developed "hypoalbuminemia" I would like someone who understands its implications to look into the meds he was given the Albumin, and possible implications of the NICE study. There was one day when Don received four units of blood 5.30am; 8am; 16.30pm and 19.00pm…this need for blood has never bee explained…why so much? I was there as mentioned previously when they squeezed it is as if it had to be delivered immediately. I never was told nor understood what was going on. I did ask…but answers seemed vague.

I just can't read notes too often this happens…have to wonder how they can all read each other's notes...must be a lot of guesswork. This is crazy for ICU or anywhere.

I was not told by nursing staff and doctors that Don had now developed a **pressure area** under his scrotum. A nurse came to me days later and told me "on the quiet" in the waiting room as if it was a secret…. This is crazy. I nursed him on my own at home at one time in our 25 years since his accident…he was stuck in bed for 6months. He

developed not one mark on his body, because I turned him and noted any problems and made sure he was dry. We were always hustled out for the turns...I don't know why I went outside and didn't stay inside to watch...I felt like I was on auto pilot too much of the time.

An odd occurrence 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 so relief and rest and I prayed for him to have any respite at all from the dreadful suffering. But then he became hard to rouse. I went down and had some tea but had the feeling that I should go back up. Lucky I did because the nurses and Doctors were all gathered about him and no one could wake him. The doc took me aside and said he may have had a brain bleed or something 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... I called the girls when they took him away, and sat with Melissa and someone else 9can't recall) in the waiting room. Later when they bought him back, 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 doc was stumped as to why he woke up after being unconscious. It was truly amazing... he smiled for hours. Beautiful smiles. He tried and tried to tell us all something and we tried to understand, but the trachea meant we couldn't hear words but just realised something wonderful seemed to have happened.

(Funny thing is that days later in the very next room to Don a man called John green had EXACTLY the same occurrence...he became unawakeable, everyone was panicky and he was taken of to have a CT scan only to return wide awake. I have to query could there have been something contagious or to do with meds, which happened to both of them...it is too odd)

Doctor's notes about this are illegible

13/5 Don is back to the suffering and is so very agitated. I look at him for so long sometimes and wonder how we are going to get out of this horrible place. The wards and the little room are dirty and the only colour is where I have put up large copies of family photos and of the creek and dam and our trees. Sometimes I see Don looking at the photo of his two sisters Jeanette and Judy (both passed away) and then looking at the photo of his own two daughters and he looks so sad it breaks my heart. He has been such a wonderful dad, and husband. Always our welfare came first and he would often bring home little treats, or buy the girls a set of earrings or something... just for the pleasure of the giving. To see him like this, in amongst the filth 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 have taken more care. He was nowhere to be seen.

It was on this day that we again requested that Don have his hair washed. As previously mentioned this only happened once in ICU in 5 plus weeks. 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 everyday and took care of as much of Don's personal care as I could, which would have given his nurse (one each per patient) a bit more time.

Oh well not important now, but it was very important to him at the time.

We now come to the end of Document C.

The next days 14-17th inclusive need to be dealt with separately, because of some issues needed to consider. He is to remain in ICU till 17th, the day he was taken away from the ventilator.

Document D 14th May 2007 till 17th May 2007

The last four days of the time between 11th April and 17th May were bizarre. On reflection our daughters Melissa and Alison and my sisters Veronica and Jackie and myself felt as if we were a part of an orchestrated event, and are still puzzled by this time.

14th May. By this time Don's lungs were drowning in infection, apart from all the fluid, which was building up, and being drained from the right and left pleural areas of his lungs. He was grossly oedematous. He had a pressure area. He had Sepsis in his body from all the infection. He had developed Hypoalbuminemia. He was unable to be weaned from the ventilator as a result of the damage done by the failed Pleurodesis operation. They finally admitted that Don was dying, something we had accepted since those first days in ICU.

In all the time since Don had been in RNSH and with all that was going on I think that up till this time I had come across a Social worker once but can find no notation about that meeting. When I told the Port Macquarie Social Worker this she was shocked, as she had assumed this would be not be the case with such a serious illness.

Now we were about to be drowned; almost assaulted in a sea of "concern".

I can not read the notes written by three doctors 14/5 but they are important as they describe Don's condition I would ask that someone please be able to go through these notes and have them made accessible so that we the relatives have some chance of finding out just exactly what was happening.

The same goes for Dr Mahader's notes written just after these three doctors and again the doctor's comments need to be able to be understood.

14th/May Dr Tooley met with me and (finally) Margaret Bramwell <u>THE</u> social worker and Don's nurse. (see Doctor's notes 5.30pm). Basically it was explained to me 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 and asked that all effort be made to get him home to die as he hated RNSH and would not want to die here. I explained to her that any decision about Don was to be made by Don and only him and that she should talk with him…her notes mention that when she explained his reality to him, "he has looked at me as if to say, 'it took you that long to notice?' and expressed excitement at being able to go home to die."

So now after all these weeks of suffering all Don's treatments apart from pain, antibiotic, and fluids were stopped and Don became almost immediately more and more lucid and calm.

They were to organise a home ventilator and we had agreed that this be taken away at some time after Don arrived home. They said they would try and organise an ventilator from Port Macquarie for home, so that Don could have some time here and then choose when to turn it off.

He was told that it was likely he would die a couple of hours after turning the ventilator off.

From this time till the day I left late 16/5 to be home so that Don could arrive at the house 17/5 we had too many people talking at us. I recall one person but can't recall who go right up to Don's face and say "You know you're dying don't you" and then seconds later the social worker 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 as Don the girls and I had such little time to be with each other and it was so precious. Like most of the time at RNSH the 16th was chaotic.

Again my skin seem to feel numb and tingly and when I spoke I felt as if it was coming from somewhere outside of me. Much of the time I was on auto. People seemed to be crying all round me, except Don, the girls and I it all seemed to be chaos. My daughters have also told me that they felt this way.

He instead became a very still and quiet well of peace and constantly indicated his concern for the welfare of our daughters, myself and my sisters..

At sometime here, Palliative care were introduced to us, but I saw so many faces I was never sure who I was talking with... almost none of the staff had name tags.

15/5 The nurse who was on duty when I came in in the 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 cruelty to Don I went to see the Nursing Unit Manager (NUM) and explained what was going on and asked she please be replaced in the circumstances. The NUM informed me that "sorry that nurse hadn't been informed" one would have though she might have read the previous notes.

She just seemed to disappear after noon, thank goodness.

The speech pathologist
Here is the joke… at 4pm 2 days before Don was to die a Speech pathologist arrived. Unbelievable. After 5 weeks in there unable to communicate, weeks after the Trachea they send a Speech Pathologist to Don

.

Just wonderful and a real smack in the mouth this was. She become quite short with Don…I had the feeling she though he was a hopeless case and her 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."

There says the wonderful and absent for 5 weeks speech pathologist

I would like a direct apology from whoever sent her. She treated Don as an imbecile. He was too sick to do much at all but he understood and he shook his head when she left the room. He was so dreadfully ill by this time which seemed to go right over her head. She acted like an idiot and she should never have been sent to him at this late date. He was days away from death which we all accepted. She should never have acted as she did.

Saline off Lasix on
An incident happened either 15/ or 16/ when a nurse who told us to call her (she was African) was on. My sister noticed that they had stopped his Saline drip, which was delivering fluid. Someone may have had the bright idea he could drink but he was unable to get enough into him that was at this time. My sister (who is a renal dialysis nurse) noted that he was on a fair bit of Lasix. She said if this continued the results would be like torture for him as he would become extremely dehydrated and could quickly go into renal failure, which would make him feel really sick.

So we chased the nurse down (she was his nurse and he was her only patient) and asked her to reinstate the Saline. She wouldn't. We asked her to ask a doctor to reinstate the Saline. This never happened. She appeared very unwilling.

Then I went doctor hunting throughout the rest of ICU and told the doctor what was happening. Later the order was given to reinstate the Saline.

We did not need this stress at this time, and Don after the awful time he had had did not need to be made suffer more because the nurse seemed unwilling to ask the doctor to do anything.

...cial worker announced somewhere around early afternoon that they had ...ements for Don to be flown home 17th. But that I would have to be there to ...ambulance, which meant getting home on 16th with the air mattress which ...y under Don. It was a nightmare of organization trying to get all the gear ... figure out a way home. At first thought to fly but air mattress made that

...onica, Melissa and I left Sydney at about 7pm, by rented car.

... had tried to spend as much peaceful time as I could with my husband, but ...ned to become full of people, on and off all afternoon.

... told that they could not find one home ventilator in all of Port Macquarie, ...r Don had to travel home with would be taken away as soon as possible ... bed at home.

...e to this, Don and I. By this stage we would have agreed to anything so ...ome home and be with family properly. Although we agreed, I don't ...hat they had the right to ask for such an agreement. It had elements of ...seemed a very callous agreement for Don and I to have to make in order ...me.

...ve home in the daylight at our beautiful place out of town. My sister ... up with him so he would always have someone he loved and knew ... youngest Alison had stayed next to him as long as she could the ...nd she flew up to Port Macquarie the next morning.

...st thing I ever did to walk away from the hospital, knowing Don might ...e.

...ve home till coming on dark the 17th. We were all there, his daughters, ...s, the Palliative care nurse, another nurse who was to stay and Dr

...was settled in his bed, the Air Ambulance began to ask for the ... We were "allowed" about 5 mins with it on and Dr Stewart proceeded ...d move it away.

... daughter Alison and myself saw Don put his arm out onto the ... back (Don was not able to talk clearly due to the Trachea). It ... he was asking to hold onto the ventilator a bit longer… which

in his case was his right. It was his choice when and how long before he died. We always retain that choice. To then have that choice taken away seems to me to be a crime against his human rights. I believe Don's Doctor should have acted on what Don wanted at this time, not what was "agreed". Can there be such agreements made in this country?

To this day the three of us do not know why we didn't stop them taking the ventilator away when it was clear Don needed it a little longer. What harm would it have done for him to be able to wake up in his own room, or just have a little longer now he was surrounded by those who loved him? We seemed to be moving in a fog...sort of in a shock state.

We have compared what we felt and it was as if we were in another reality and were not really functioning properly.

D took Don's arm off and away the ventilator and gently but firmly tucked it in under the blankets.

I have trouble with this incident. The whole thing felt to me like an execution. I expressed this feeling to the Palliative care nurse. Although Don was dying, it should have always been totally up to him the time frame, unless he died naturally as God willed.

Don was with us awake for two hours then went into a sleep and died about 9/ 9.30pm. He died with much more dignity than was ever shown to him during his time inside the NSW Health System.

None of any of this should have happened. The whole long suffering and cruelty my abused husband endured would never have happened had and others considered his situation and what they were trying to treat properly.

There is no excuse for their actions. There are no excuses for the filth and chaos of Royal North Shore Hospital; the lack of accountability; the lack of continuity; the lack of real disclosure which has only happened now we have all the notes, X Rays, CT Scans; and Pathology.

The girls and I know what was done to Don. We don't have to prove anything. What we want is for the Doctors who treated him, especially and the respiratory team, those nurses in Ward 7D who neglected him till he developed Respiratory Arrest; the system at RNSH which allows a hospital to run at such a desperately dirty and chaotic level where there is little continuity, notes are illegible, the list could just go on and on.

We don't need to prove anything. What we want is to know why and how all of this was allowed to happen to a man who had stoically suffered so much for so long and had the right to expect to be treated properly and with dignity.

On behalf of Don's daughters Melissa and Alison Mackay and myself Therese Mackay and all the family and friends who loved him.

Melissa's Statement Coming

15/10/07

Our daughter Melissa sent this through recently – she had been unable to write her experiences of her father's dreadful treatment at RNSH as it was too upsetting. She put this together nd then the dam broke. She is close to finishing a longer complaint which will go with mine…but for now this stands.

"hi mum,
i just remembered when dad was in icu, i'm not sure if you or veronica were there, in the room with the harsh english nurse, when dad was vomiting because of his medication . It was all over his face, pillow, and he was cold from it and she kept getting annoyed because we kept asking her to suction it out of his mouth so he wouldnt choke. and we tried to clean it up and asked her for some towels etc and she said no ... the lifters will clean it on their next lift round. (whenever that was to be) finally she gave him some maxalon and he settled, we kind of cleaned up as best we could. can you imagine how he felt,the taste in his mouth the smell, and you know how you get cold when your pillow is wet. . . did you put in your documents when dad bit thru the tube when they realised he had staff, and we heard his voice and he said "help me" then we were told to leave the ward, he was fully awake then . anyway just some things that came to me last night thought i'd tell you. i love you very much mum. big 4! "

Melissa Mackay

"

Her full Statement is following

My sister's statement

Don Mackay

Jackie (Anne) Spencer's Statement for the day of May 17th 2007

My name is Jackie Spencer and I am Don Mackay's sister -in –law. I was asked by my sister to stay with Don on the 17th May 2007 at Royal North Shore Hospital until the Air Ambulance was able to take him home to Port MacQuarie where the ventilator was to be removed.

I arrived at Royal North Shore Hospital just after 8.00am. Don looked very tired but was relieved to be leaving the hospital. His transport home was to be around 9.00am. This was later extended to 10.30am.

Don was very anxious to try and communicate to me. Because of the procedures (which have been noted) he was unable to speak. The nurse on duty whose name was 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.

The message Don was conveying was that he wanted to make sure that his family would look after Therese 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 that this comforted him. He was tired but calm.

The transport was then rescheduled to around midday-12.30pm. Don was very tired. The air ambulance then offered me the option to travel with Don in the aeroplane. Don seemed relieved to have me stay on with him.

Don's room has that day for the first time been 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.
Around this time a hospital staff member came to the entrance to Don's room looked in and sprayed a substance into the room and on the floor. There was no explanation and Don saw the incident.

WHY? What was so infectious in his room as all the men in there had MRSA and others? Why this?

Don's Doctor and Rebecca the nurse during the morning took Don off the ventilator which he had been on and then put him on a portable ventilator which was to accompany him on the aeroplane. Don was experiencing quite a lot of discomfort with the tubes of the ventilator. Rebecca spent quite a lot of time trying to make Don comfortable.

The Air ambulance was delayed again. Departure time around 2.00-2.30pm. Don looking very tired, I think it was around 3.00pm when the retrieval team arrived. A very competent but kind air nurse took charge along with two ambulance officers. Don's doctor returned to see him off. She told me it was her day off. She kissed Don goodbye.

Don was wheeled out to a land ambulance which drove us to the air ambulance. Fortunately I was positioned at Don's head and I was able to steady him for this part of the trip.

Don was then transferred to the aeroplane. There was the pilot, Don, the air ambulance nurse and myself making the trip to Port MacQuarie. The nurse pointed out the harbour bridge and other scenery but Don didn't look. He looked very relieved, serene. Don was focused on my face. I was sitting at the back at the aeroplane and fighting very hard not to burst into tears.

Arrived at Port Macquarie around 5.00pm. The nurse was impatient because there was no land ambulance there immediately. They came a few minutes later. Incrediblely Don had made the trip.

Don was then transported to his home.

Jackie Spencer
25.09.07

My husband and our children's
Father Don was not just another
number lost in a sick system.

His life was sacred and precious.

His suffering was prolonged and
brutal to witness – how much more so
for him.

He was loved and he was a unique
individual.

The next pages just give a brief insight
into the man we loved and who loved
us without conditions.

Just a very brief insight -

DONALD WILLIAM MACKAY

4TH JULY 1950 - 17TH MAY 2007

Don's Eulogy

This was read at the funeral by the celebrant.

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.

With Love Therese

Read by
Ian Mackay

The dash between 1950 and 2007 is the period Don was with us. It is the most important dash that we know. It fulfils his life and the love that we know both from Don and to him.

My portion of Dons life is mainly from birth till his early twenties.

BORN on 4th July 1950 the fourth child of Rod & Kath Mackay in the western town of Moree. His family consisted of firstly
Jeanette... (Tet)
Judith... (Jude) and myself
Ian. ...
Not counting the main proponents of the family Dad (Rod) & Mum (Kath).

My sisters used to dote on me until this kid called "Don" arrived, it changed after that and he became the dotee. That didn't matter all that much as they couldn't play marbles and didn't go much on catching frogs.

Not much to do in Moree,

One evening at dinner not long after his first birthday Don said to us and all,
"We should go to the Snowy and build the Eucumbene Dam as they need people like us" He was a very advanced child. As a group of half a dozen we set off to build a dam. Turns out it was a bit bigger than the six of us could handle, so we called in a few more people (1000 actually) it took about six years to complete.

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 sent you to a home of some sort or other. It included, the four of us setting out for a bike ride of a lifetime, ending 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) in a raging stormy freezing cold on a 10 mile ride in the dark, with the cavalry Mum & Dad the three eldest – me included were chastised severely. "What were you thinking taking this young baby out in this weather". As quick as Tet said "Mum at least he is warm and dry and he is not a baby he is four years old. It ended well. The kids could do no wrong.

The Shooting,

Don & 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 GREENY ATTITUDE. Not content with the foot shooting when we got home he reloaded the slug gun and chased me around the house.

Fishing

A mate and myself were going fishing and knocked off a bunch of carrots from the headmasters place to eat while fishing next thing Don and his mate Ian 'Ackenzie' his real name was Mackenzie but Don couldn't get his tongue around that, caught us and dobbed us into the headmaster- Mr Faulkner. Don got extra points for that. The mate and I panicked when called to his office, but being a great teacher he didn't go crook instead gave us a lesson on tying fishhooks.

The remainder of our stay in the Adaminaby Dam site was filled with family love and love of family a really great place to grow up as a child.

Dam completed Don called us together again and said that the people were having troubles with a dam at Tan Tanungra and felt that we should help a fairly uneventful part of our lives Don schooled at New Adaminaby. Tet worked with Dad and Jude helped mum at the local shop.

The remainder of his story is related by Therese through Garry our celebrant.

To have known Don as a brother was a privilege and to have loved and be loved by him irreplaceable.

DON REST IN PEACE, WE ALL LOVE YOU.

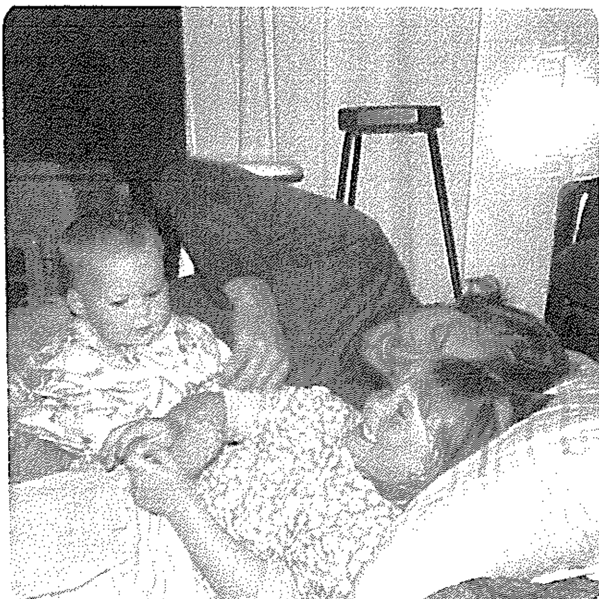
Therese's part

Don, from 1972

Don and Therese met in Newcastle in 1972 and joined forces about three weeks after that meeting. Don was then working as a Fitter for Hodge Industrial installing underground petrol tanks and bowsers all across NSW.

In 1974 Melissa was born to them and Don's boss offered them the use of a large caravan to use so that Don would not want to come home each weekend to be with his family and could spend months moving around NSW working.

This was a wonderful 18 months and there were few areas they did not get to spend time. Blayney in winter in an uninsulated caravan was an experience. Opening the van door at the tick gates and seeing their red kelpie, called Red, slithering around in the beetroot which had fallen out of the fridge, because someone had forgotten to put the pin in the fridge door was another.



Port Macquarie was one of the towns they visited and Don was offered work from Gordon Hunt should he ever move here.

In late '76 they moved to Port Macquarie.

Alison was born in 1977 and the family was complete.

They lived in a small house just past Sea Acres near Johnson's Fruit shop, which cost $12 a week. Here they were home. Chooks, ducks, a dog – Boris, cats – (Don was never too keen on these creatures) and Lucky -

Don again gathered us after our Sunday roast and weekly caster oil and said, "there are problems with a power site at the Lake Macquarie we should go and help"

Swansea this joint had it all
TV - never seen that
Beaches - been on holiday
Lakes - made them
Fishing - caught millions and masses of adventures that four kids from the Snowy had never seen.

Don became a super star at Soccer in the under 14s and we both completed schooling there. From there the family fragmented.

Tet married Jack Holmes and had a son Phillip all died in a car accident 1969.
Jude married Buddy whom died in a car accident in 1965.
I married Monika and had a son Terry and daughter Jenny.
Jude remarried, Kevin and had a son Rodney and daughter Joanne.

Don said they were calling from Port Headland in WA. The family fragmented further, as mum and dad with Don in tow headed there to sort out the problems the Port mob encountered.

The problem solved and plans to return to Swansea were completed. However Dad encountered cancer and lost the battle in the Sir Charles Gardiner Hospital in Perth on 31 Jan 1966.

Don and mum returned to the eastern states, I got leave from Vietnam to see Dad before he passed but unfortunately due to slow transport missed seeing him before passing. My leave was far to short and I returned to Vietnam whilst Mum and Don went to Maroon country in Brisbane where the tied up with Jude.

With Brisbane a temporary base Don now 17 headed to Blackwater mines 4-500 kilometres west of Rocky. This part of his life was born "The wild child" bought new cars and demolished them at a rapid rate.

Mum returned to Cardiff and Don soon followed and sort of lost the Wild Child a bit when he met

Therese and had two daughters
Melissa in 1974
Alison in 1977.

Don's horse, two happy little girls and little money made this a happy home for Don and Therese

He worked on building sites and drove a backhoe and truck and was able to turn his hand to most things he tried.

In 1982 Don was badly injured while working in the canals behind Settlement City.

He became a quadriplegic and spent a seven-month stay at Royal North Shore Hospital (Sydney). Therese, Melissa and Alison moved for that period living near the hospital, with Therese's eldest sister Veronica. All returned to Port Macquarie when Don was well enough

After a settling period, Don along with his wife Therese became involved in issues in which he believed in passionately. He lobbied Council in the '80's for better wheelchair access and struck a deal with them that he would go halves in the cost of construction of wheelchair access on major access points around the CBD.

In the early '90's he manned the RSPCA phone and was passionate about his commitment to this. Although it's a well known fact 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.

His mother died in 1997. He not only looked out for his mother's needs but also Therese's mother and was always quick to see when others were had difficulties. He had a great compassion for others who were suffering illness or other.

When his sister Judy was dying in Queensland in 1998 he and Therese 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.

He believed ardently in the right of the individual to freedom of choice on issues regarding Fluoridation, and other and it is well known he did not suffer fools gladly. He was very active in the fight against the privatisation of Port Macquarie Hospital and he worked for years tirelessly to have the hospital returned to public hands.

Unfortunately he was stuck in bed on the day the Hospital Action Group had its celebration outside the hospital grounds once again when the hospital was finally handed back to the people of NSW in 2004, but he spent that morning harassing the local media, as was his wont, into speaking with the Hospital Action Group who were there from the beginning of the fight in early 1992.

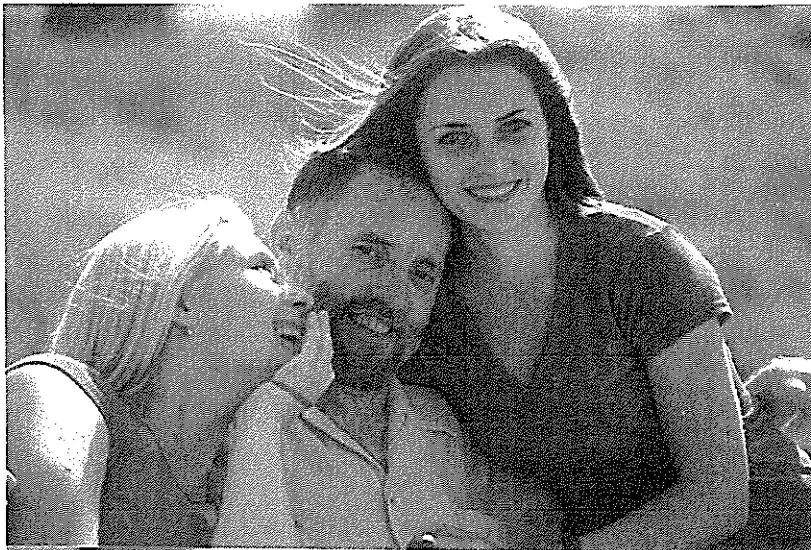
He became actively involved in One Nation, and along with Marge Rowsell from Taree organised the original meeting in the Civic Centre when Pauline came to Port

Macquarie and filled the Civic Centre to overflowing on a Tuesday morning. When Pauline moved away from One Nation so did Don. He was outraged by her jailing and worked as hard as he could writing letters etc to help raise awareness of the injustice often saying that if it could happen to such a public figure as Pauline, it could happen to any one of us, and that we each, on our own, must always fight against injustice when we are able…
When Pauline was released, fully exonerated he was over the moon.

Don and Therese moved out here to Craggy Island in early 2004. The sense of peace and beauty they both felt the first day they saw this place is still here with us and for Therese it is the essence of her husband and a fitting place for this service.

Becoming a Quadriplegic was bad enough, but Don was unlucky in that he was suffered constant pain and would comment on those few days when it totally lifted how good the day was. As the years went on this 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 bravery he showed by just facing the days at times.

The family are aware of the many roles Don played in life and on the small screen, where just the placement of a wig, or a hat and he would transform into little fat Eadie from Picnic at Hanging Rock which should now be known as “Picnic at Don Rock”…and his Mafia alter ego called “The Don” was done as seamlessly as he did everything.



There was the eighth day of the week “Don Day” which was a special day for the kids.

His force of personality and its many facets became something of a miracle to his family and especially Therese, Melissa and Alison. He was constantly concerned

about their welfare, and that of the extended family, and he seemed to grow more compassionate, the more he suffered.

Melissa and Alison joke about the fact that they quickly learnt to never say they were bored because when they did he would give them jobs to do. Now adults they say they are grateful for this. He was fiercely independent and a gentle and concerned loving husband and father.

He passed away at his home on Thursday 17th May, two days before his eldest daughter Melissa and her fiancé Chris were due to be married. He had been in RNSH for 5 weeks and was flown home the night of his passing. Unable to speak because of the Ventilator for the past 5 weeks, when it was finally turned off, he softly talked and joked with those of us gathered for about two hours. He died with his family around him and was loved gently as he went with dignity and concern for others welfare the last things he expressed.

The manner of his passing after the terrible suffering he endured, will never be forgotten by those of us present, and has left us with no fear of death… none at all. Yet another of the precious gifts he left to those he loved. He was beautiful to the end and died quietly with his daughters and wife and other loved ones… in a quiet room... at home at last. He deserved such a peaceful seamless death to this life. His compassion and empathy for others; his sense of fun and stirring; his generosity; his unpredictability; his intense love of the natural world; so much, but more even was the love he held for his children Melissa and Alison, and his wife Therese. He loved them without conditions. Its known Don had his rough edges but the rough diamonds are always the best, and are always more precious

Thanks must go out to Therese's sisters Veronica, Joan and Jackie for their support. Jackie spent the last day in the hospital with Don while the family drove home to meet the Air Ambulance. She went on the flight with him so that he always had someone with him he loved. Thanks to Carmel, Patsy, Mike, Rod, Neil and Renata, and Donna, and they know why.

The effort made by Don's Doctor Dr Mark Stewart and the Air Ambulance and others made it possible for Don to have his last wish, which was to die at home.

He is survived by Therese his wife, Melissa and Alison his daughters and Ian his brother.

Goodbye for now our lovely Eadie... See you round like a rissole.

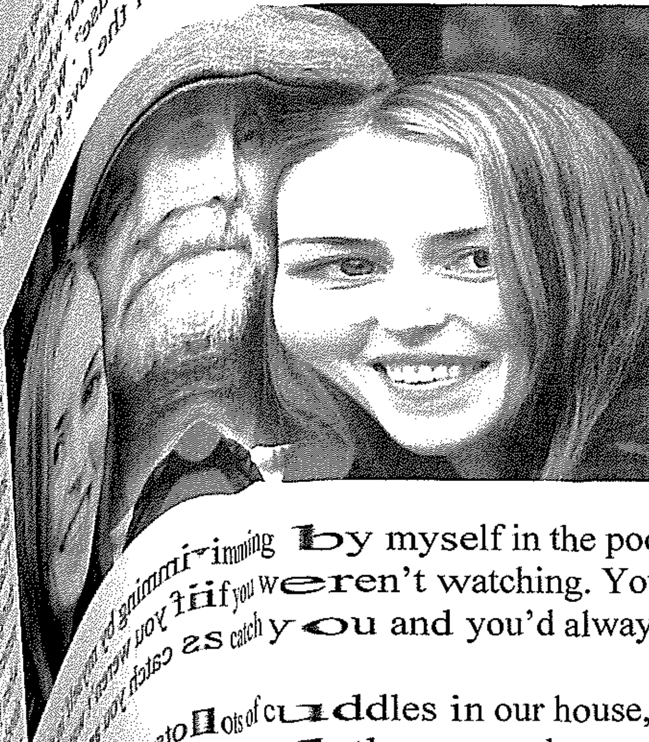
Melissa's part

One things for sure this world will never be the same again without Don or better known as Noddy to Ali Mum and I.

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. Ali do you remember your first communion? I know mum and I sure do! Only 20 cents for a glass of water. 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, YOUR 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.
He deserves all the wonders of complete freedom and happiness.

Melissa Mackay

when trying to say goodbye, or a final “see you later” to you Dad? I always be with me & that I will meet you again, but for now you so sorry for what happened to you at Royal North Shore Hospital, it hithouse”. We were lucky to have been with you at the end. I hope all the love from us.



You & Mum gave us such a fun & rich childhood; there was always much laughter in the house. There are so many stories and great times that will always be with my heart. Thankyou for teaching me so many things its strange but I still remember each moment so clear when you taught me to tie my shoelaces, to dive properly into the pool, my times tables, telling the time on a real clock. All the times imming by myself in the pool because I was always to scared if you weren’t watching. You would try to sneak away after a long catch you and you’d always come back out.

lots of cuddles in our house, interesting games of monopoly, jobs boredom, and there was always a right way to do jobs and a short time them. That was just you though Dad and it became slightly older.

many home videos of us four and others, but by far the best was Rock!” you played Edie brilliantly and we have so many one- will always make us laugh.

always being so helpful and kind to me. You always tried to make All the phone calls over the last few years I will cherish. All the the silly voices we did. You taught me how to cope with things

... of Donald McKay at the Royal North Hospital

... Therese McKay for thirty years. In the ... funny, articulate and cared for his ... him. He was an active member of his ... for many hours for local and state

... you know that the man I saw in that ... Don that I knew.

... him the day before he went to Royal ... jokes and was full of hope and ... wedding.

... Royal North Shore, in Sydney. The ... hospital is old and in need of ... extremely dirty.

... care ward where Don was. A ... number from the waiting room

... old tables and chairs, bins full of ... dirty windows. While waiting I ... paper all over the floor. The sink

... years, so braced myself for ... prepared me for what I saw.

... lay in bed with tubes ... in his mouth. There were no ... a box with one side open. ... at comfort, and most of the

... my hands and put on a plastic

I hoped he knew I was there. I talked about old times, the wedding, anything. I would read to him to try and comfort him. Because 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.

On 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. I asked the nurse for help, the nurse did not have a clue. She showed him a card with drawings on, so he could point to what he wanted, [they untied his arms] 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 and night. I never saw anybody there all the time. The ones I did see some were sensible, some very dismissive, some downright rude and, treated him like an idiot.

One day when I was there I had to go the chemist, which I was told was in the private hospital, opposite Royal North Hospital.

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 fifth 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 happen; he only went to the Royal North Shore for a lung drain. He ended up with collapsed lungs and a body full of infection from the treatment he received.

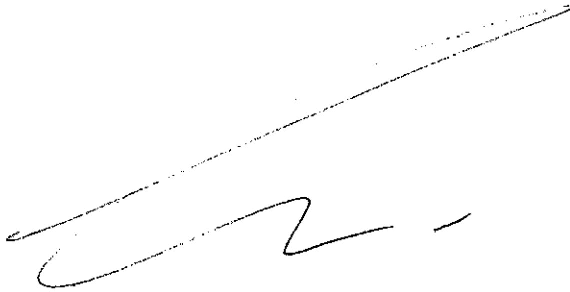
(3)

His last days of life were filled with distress.

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

Thank you

Carmel Lewis



Carmel Lewis
2 Cathie Circuit
Lake Cathie
2445. N.S.W.

0265 855189.

Veronica Spencer's Statement re Donald William Mackay

My memories of the periods 15/04/07- 25/05/07 and 15/05/07-17/05/07.

I am Therese's sister and 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 Dons 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. It felt like the preparation for an execution. 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 Dr , the man whose job it was to fix his problem.

After that encounter Don's inevitable path to his plot in Wauchope 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 the diseased Royal North Shore Hospital.

Here are some memories that are particularly vivid for me:

I worked in the Haemodialysis Unit at RNSH in the mid 80's and although I encountered bullying there the hospital was clean and seemed to me to be providing a competent service to its clientele.

This time even before I went inside I was struck by the faded, mottled dark grey/brown of the exterior. What ever 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. Royal Brisbane, 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 dining room to get the windows cleaned. This disappeared rather quickly no doubt management were shamed.

On the notice board en route to the dining room 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 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.

I passed some rooms in which there was piled up furniture. From memory Don's ward in ICU was a trip back to the 80's- 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 RNSH 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' carpark used to be- the salubrious Private Hospital. Before RNSH 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
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. Dr.
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 she was told we'd had our conference. Therese's request to have high doses of Vit C included in Dons 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 RNSH with a moderate R. 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 I : but failed to be worthy of his attention at this stage we got instead the Cardio thoracic Registrar 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' imagine that he would have been able to fully understand English as he explained the risks that Don, a quadriplegic with limited respiratory would take having the procedure. No doubt he would have said to Don even though diagnosis of the effusion's underlying always should guide treatment; since you are a quad. whose quality of life really isn't that great we are speeding things up for you and wont worry about the cause. Possibly he would have said we are doing biopsies at the same time, which is contraindicated. But what the heck.. go for it Don!

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 machine delivered mandatory hyperinflation at regular intervals. He was clearly struggling. His tongue was out but curled under- looked like a lizards tongue. Therese was alarmed because this was the type of breathing he had before his original respiratory arrest (which was ingnored 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 it how fast his breathing was. She had told us he was trying to talk but blood gas proved other wise and he was put back on the ventilator.

This set me off seeing Dons encounters with Medical Staff in terms of a Hieronymus Bosch painting. 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 RNSH in his last week. The Social Worker Margaret, 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- 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- 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. My last Hieronymus moment was when a nurse called Baba was going to give Don Lasix but had I saw they had taken his IV fluid away. 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.

I question the legality of the choice Don had to make. He tried to keep the ventilator on at the end- with dignity of course. The LMO in Port Macquarie put Don's hands under the covers. What a choice. At least until he saw his place in daylight. That had been the aim of the day to get him home in daylight.

This last stage of it all becomes an El Greco: long shadows, long, pale faces, Dons long, grey cap, the cluttery old respirator that would have done Hieronymous proud (NSW Health Service property however), my younger sister Anne (Jackie) dressed in black seemed to have lost weight on the trip with Don . He seemed to have become paler and thinner beyond description.

Veronica Spencer.

Statement by Melissa Jane Mackay concerning the treatment in Royal North Shore Hospital and the subsequent death of her Father Donald William Mackay on 17/5/07.

Its 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 (Pleurodesis) no one had any knowledge of) that was performed within hours of him arriving at Royal North Shore hospital. Then 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's had the Pleurodesis on Thursday. He was in the Spinal Unit in a room with another man. He was agitated and he was talking unusually. Mum took a photo of him and I together. This is the very last photo of him. 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 at about 4am and said to come in immediately. I got there soon after she did. Mum was staying at the Greenich Inn near the hospital. 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 Dr Delaney coming in and yelling 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. You were there with me. His nurse that day was the harsh english nurse. It 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 a 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 Maxalon 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.

We had continuously asked for him to be allowed Intravenous Vitamin C. Dr Delaney and the Pharmacist had no problem with this but a new Doctor 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 Indian doctor and a nurse. Also 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 1,000 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.

Unfinished 23/10/07

Melissa Jane Mackay