

# The Inaugural Lecture

On 21 June my friend Robin drove me into the medial legal unit to attend Professor Jo Manning's Inaugural lecture on "Compensation for research-related injury in the UK, Australia and New Zealand: a legal and ethical audit". Leading bioethicists, national commissions, and leaders of the medical profession around the world have argued that society owes an ethical obligation to compensate for research-related injury, and that no-fault compensation is the best ethical response.

My friend Betsy snapped a picture of me, my ex-husband Bill, and Professor Jo Manning after the event.



## **UPDATE FROM LUKE:**

I received a lovely email update from Robin, Betsy and Dad on how the evening went. There were few details worth mentioning that Mum left out:

## **From Bill:**

*Jo Manning is a member of the Cartwright Collective, and made a very nice acknowledgement of Lynda's work at the start of her lecture (which marked her inauguration as a professor at the law school). In fact it was Lynda's observations that triggered Jo's research on compensation for patients adversely affected in clinical trials, which was the subject of her lecture*

**From Robin:**

*Jo came to Lynda immediately after her presentation and told Lynda that if/when she/they are successful in getting the law changed in NZ so that "no fault" compensation is, in the future, awarded to all those who suffer the misfortune of injury by reason of medical trials, the new law will be called, "Lynda's Law". Then she added, "and I mean that", and gave Lynda a long hug.*

*For me that was a moment I feel so lucky to have witnessed. I feel glad and privileged to have been able to play a small part in helping last night go smoothly and I am very proud of being able to call you my friend for 42 years of my life, Lynda.*

*You are a magnificent woman. You have made a difference in your life – to young families and their successful birthing and nurturing of their babies, to every area of women's health, as National Women's Hospital advocate to assist the communications and successful outcomes for hospitalised patients and now, in what is perhaps your finest moment, an advance that will potentially progress positive and fairer outcomes in the future for all NZers who offer themselves for trial in the process of advancing medical science and consequently producing healthier outcomes for all NZers.*

*This was a wonderful culmination of your career, Lynda.*

*Arohanui, my dear friend*

Thanks very much for passing these comments on – and giving me permission to put them on the blog. The family was very touched to hear this ☺

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## [A week in hospice](#)

Last Monday I was admitted to the West Auckland hospice in order to get the nausea and pain medication sorted out. It was so much quicker doing it in hospice. By the end of the week we were making plans for my discharge back home which occurred very smoothly. Over the previous few days my children had drawn up a spreadsheet sheet for family and friends who wanted to be on the care roster. The hospice staff were very impressed with how it all went and asked to have a copy of it as a guide for others. My first night at home went well and I quickly adapted to all the bird songs that surround me first thing in the morning and last thing at night.

Looking back, I think it would have been best to come in to the hospice earlier than I did, but I am inclined to be rather stubborn and this was another example of my being stubborn rather than sensible.

And this week I have a very important event on my calendar – an Inaugural Lecture to attend which I am very much looking forward to.



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## Plan B

The hospice team visited me on Tuesday and we discussed options. Their first and preferred option was to admit me to the hospice for 4 – 5 days to sort out my pain management issues and to rehydrate me. But I want to try something else first – as over the weekend I started to realise that increasing the dose of quick release morphine pills was beginning to work. After a discussion of my experience over the weekend, my preferred option is to increase the dose of both quick and slow release morphine pills, and double the amount of Sativex I am having. I am going to keep the admission to the hospice as my back-up plan. And there are also a couple of other more intrusive options involving a brief admission to hospital – hospital not hospice – that I have for further down the track.

And on a more optimistic note, the three of us share the opinion that the events of the past couple of weeks are not the beginning of the end, although for me there have been times lately when it has felt like it.

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## Pain and Food

Two more weeks of not being able to eat or drink anything without it causing spasmodic pain is taking its toll. The heartburn, indigestion, upset stomach, and gastric pain that follows from swallowing even a sip of water has become more than I can bear. Some nights the pain is excruciating, and nothing I am prescribed seems to work. Both Mylanta and

Gaviscon cause immediate projectile vomiting. Taking paracetamol with my top-up Sevredol pills makes no difference. And Omeprazole and Domperidone don't prevent the nausea or pain either.

Knowing that anything I eat or drink is going to result in pain is a huge turn off. I crave things like a glass of water, a cup of tea, a yoghurt milk drink, but then regret it once the pain kicks in after just a few sips and works its way down my digestive tract.

The hospice nurse and doctor visited me at home on Thursday, but the regime they put me on made no real difference. I learned that Mylanta caused me to vomit violently. When I contacted the hospice over Queen's Birthday weekend and was put on Gaviscon I discovered these antacid tablets did the same thing.

I feel myself getting weaker by the day and I am now desperately hoping that there is a plan B that will work and get rid of the pain. I have survived the long weekend and now have my hopes that the hospice team will be able to make the pain go away.

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## [How long have I got left?](#)

This is the question that haunts me most right now. It is impossible to ignore. It's feels a very strange place to be, and this has been heightened over the past week or two as I struggled first to get the pain back under control, and then to work out why I was feeling unwell. An increase in the dose of the M-Eslon pills I am taking twice a day eventually resulted in my being pain free again, but it took a while for me to realise this as for the past week I have had no appetite

and been vomiting daily.

After several days it occurred to me that I may have caught the “tummy bug” that some members of my immediate family have had. It is hard to know what exactly is wrong as my tendency is to immediately blame the cancer for any unpleasant symptoms I am feeling. And I did this again last week as I struggled with trying to eat anything and then with the discomfort, nausea and vomiting that followed several hours later.

Thinking it was the cancer I felt a sense of panic as I was aware that I had yet to finish my Advanced Care Plan (ACP), and to start organising my funeral. In the few hours I had of feeling okay each day, I have managed to complete my ACP and to organise another family gathering to discuss it and my funeral arrangements with my children. All last week the question “how long have I got left” haunted me, and motivated me to try and get these things completed.

I have also had my first appointment with one of the palliative care specialists at the West Auckland hospice centre, an appointment made to discuss my pain relief options. The increase in the dose of morphine eventually resulted in my being pain free, but I think it took a while to take effect as I was distracted by feeling so unwell. I am still not sure whether it is a “tummy bug” or the cancer, and I suspect that I may not get a definite answer from any of the health professionals involved my care. I have made an appointment with my GP for later this week to discuss both my ACP and my continuing to feel unwell. I have also arranged to meet with the person who has Enduring Power of Attorney for my health and discuss my ACP with him.

But the questions continue to haunt me day and night – how long have I got left? And have I started to go downhill already?