

## 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 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?

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## My last submission

Last week I spent a considerable amount of time working on a submission. This time it was my own personal submission. The Auckland Women's Health Council's new co-ordinator was also busy working on her first submission for the AWHC on the same consultation document – the Health and Disability Commissioner's consultation on research involving adult participants who are unable to provide informed consent to being enrolled in research.

Producing this submission gave me a great feeling of satisfaction and a sense of completion as the fact that vulnerable populations of people, including unconscious patients in intensive care units, young adults with Down syndrome, patients with dementia, prisoners, etc, are being enrolled in clinical trials and other forms of research without their prior consent has outraged me for some years. A front-page article in the *NZ Herald* three years ago about the practice had not resulted in action from either the Ministry of Health who oversee the Health and Disability ethics committees or an inquiry by the Health and Disability Commissioner (HDC). Three years of writing letters and emails to the Commissioner finally resulted in some action – the production of a consultation document. Last year as the months ticked by I felt an increasing sense of despair as the promised consultation failed to eventuate. Finally, at the end of February, the HDC released the long-awaited consultation document and I counted my lucky stars that I had survived long enough to not only produce a submission, but was still capable of being able to go all out on my own submission. This was no mean feat as the submission had to be completed on-line and it proved to be a very time-consuming and clunky process. I felt

a profound sense of completion once I had pressed the “submit” button. Whether it makes any difference is not as important as my being able to call upon my eight years of experience attending ethics committee meetings and exercise my democratic right to contribute a consumer/patient perspective on a practice that I had thought was ended by the 1987/88 Cartwright Inquiry and the release of the Judge Silvia Cartwright’s report in August 1988. The fact that the New Zealand government allows it to continue is against not only international agreements we have signed but is also unethical and illegal.

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## Four trees

Over the Easter break the family gathered together at my son’s home for a shared lunch followed by the planting of four trees. The previous weekend he and I had been to a tree nursery and bought a large kauri tree, a large pohutukawa tree and two smaller pohutukawa trees in preparation for this event.

However, the events leading up to this particular family gathering had actually been set in motion over a year ago. Some months after learning I had terminal cancer, I finally made up my mind about whether I wanted to be cremated or buried. For decades I had wavered between cremation or burial, and now it was time to decide. I chose to be cremated, and I told my children that I wanted my ashes to be buried at the place that had been my home for 42 years. They thought about what that would mean for them and some weeks later came back to me and explained that after my death they would really like to have a place they could visit. This wouldn’t be possible if my ashes were buried here at home as once the house they all

grew up in had been sold it would then be inaccessible to them.

After further discussion and some creative thinking, we found a way of my staying in the area. My third son and his wife live just around the corner from me on several acres of land which at various times of the year support a few pigs, some sheep and cattle, chickens, and two bee hives. It also has lots of mature fruit trees, some wonderful kauri trees and other mature trees. We decided that my ashes will be buried at my son's place, and in order to avoid a similar scenario should my son and his wife decide to sell their property and move to a new home in the future, we came up with a plan. My ashes will be buried in a way that allows for them to be retrieved and buried elsewhere.

Having decided on the exact spot where my ashes will be buried – next to a rock that was already there when my son bought the property – a space has been created for the four trees and the outdoor garden seat that we also intend to buy. The spot has a peaceful rural outlook across a valley that has lots of trees and only a few houses.

After lunch and in between occasional brief showers we dug four large holes and planted the large pohutukawa tree near the rock, then the kauri tree and the two smaller pohutukawa trees. It was such an amazing experience being able to take part in preparing my “final” resting place in this way – and to be doing this with my children. My ashes will be buried beside the rock which just happens to look vaguely like a tombstone.

There is one stipulation – my ashes must not be divided but remain intact! And I have full confidence that my family will be able to come to an agreement on where my next resting place should be.



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## Pain relief

Over the past few weeks I have had an increasing amount of break through pain. At first I wondered if I was imagining it, but after a couple of weeks I realised I was not. After my body adjusted to the low dose of morphine tablets I began taking in October last year, I had come to take being free from pain and what I call discomfort for granted, but now the pain was resurfacing. Just over a month ago I decided to add another option to dealing with the pain – medicinal cannabis in the form of an oral spray called Sativex. Recent changes to the process of applying to have this as a legal option for cancer patients who are experiencing pain, loss of appetite, nausea and significant weight loss meant that it was now a straight forward process for my GP to fill in the required form and obtain permission from the Ministry of Health to prescribe it for me. Unfortunately, as with other pharmaceutical industry drugs, it is obscenely expensive. However I decided to fork out an initial dollop of money and give it a go. In New Zealand, Novartis, an international drug company based in Switzerland is the drug company making millions out of supplying Sativex.

One immediately noticeable benefit was a big increase in my appetite which has resulted in my putting on nearly 3kgs. And I feel stronger and better for it. It is also very effective in getting rid of the break through pain. The one drawback is that I am currently only able to take it once a day. Twice a day and I get horribly stoned. So it is obviously quite potent. Either that or I am extremely sensitive to the cannabis used in the manufacture of Sativex. It took my body a couple of weeks to adapt to the dramatic side effects of morphine which then disappeared, so maybe it will take me a



few weeks to get used to Sativex, and I will then be able to use it twice a day.

I am now also using Sevredol as another option to deal with the break through pain, taking it once or twice a day as well as the slow release 10 mg M-Eslon capsules I take every morning and at night. My oncologist put me on M-Eslon once I had adjusted to taking morphine in the form of the faster acting Sevredol pills.

As the break through pain has now become a daily event I think I will need to increase the dose of morphine when my current prescription of M-Eslon runs out. I need to do carefully as I want to stay as alert and focused as I am now.

It is good to have options, as all drugs have unwelcome side effects, and we cancer patients have to work hard on finding the ones that work best for us. I also appreciate that the current government has seen fit to start removing the barriers to patients having access to medicinal cannabis, and that I have a GP and an oncologist who are both very supportive of my trying Sativex. I am also most fortunate that my oncologist is probably the only oncologist in New Zealand who has led Phase 1 and 2 clinical trials of Sativex, so didn't freak out when asked to help with applying for me to try this drug.