

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.





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.

Another milestone

On Sunday I will celebrate another milestone – 18 months of life since I was diagnosed with pancreatic cancer. After all I have been through over the past 18 months it feels like a significant event as 75 – 80% of us don't make it past the first year. I have been busy over the past few weeks preparing for the shift of the AWHC office from my home and helping the new co-ordinator of the Auckland Women's Health Council take over the role. We have attended District Health Board meetings and ethics committee meetings together, and she is about to be welcomed into the Cartwright Collective as we continue to make our concerns about the proposed changes to New Zealand's cervical screening programme known to health authorities and consider organising another seminar to mark the 30th anniversary of the Cartwright Inquiry.

Last week the AWHC committee treated me to a wonderful lunch at Ostro's which was much appreciated. Of course, I couldn't resist the seafood entrée which came with raw oysters, my favourite food. I so enjoyed being there with these amazing women who have been so supportive during the past two to three decades and who have been there for me in so many ways since I learned I had cancer.

So here I am in what feels like my first week of retirement contemplating my future and constantly wondering how long I have got. I managed to refrain from asking Dr S. how long he thought I had left when I saw turned up for my oncology clinic appointment last week, but it is an ever present question that is part of my post chemo life. I asked him what he thought about the continued downward trend of the blood test result for CA19-9, the pancreatic cancer biomarker. He thinks this is probably the ongoing effect of the seven weeks of paclitaxel I had in late November and December last year. I also discussed one of the other effects of that toxic drug – peripheral neuropathy or numbness in my toes and in the soles of my feet. It is extremely disconcerting. As I have had several falls and many near misses I continue to have to be very mindful of my feet when I am walking. As it is now over three months since my last dose of paclitaxel it is unlikely that the damage done to the nerves in my feet will heal before I die.

I still have much to do as part of decluttering my home and preparing for my impending death, but I am actually taking my time over this and plan to make the most of the extra hours I now have, to go to movies and read some of the unread books lying around that I have not had the time to read. Such a luxury!