

Death and dying in the media

Over the summer I have been acutely aware of the media's focus on cancer, new over-priced cancer drugs, and death and dying. I am facing my own death and dying at a time when these issues are being debated at a national level. It's a weird feeling, given that I am currently in the process of working out what I want for my own end of life care.

I have also been following what is happening to Helen Kelly who is facing her own death from terminal cancer, and sharing her battles with the health system. In an article that appeared on Stuff today, she talks about her submission to the Health Select Committee which is in the process of considering submissions on assisted dying. She makes lots of very good points, and also mentions Atul Gawande's fantastic book "Being Mortal" which describes how badly medicine often treats those approaching the end of their lives.

<http://www.stuff.co.nz/national/health/76201402/Euthanasia-debate-Why-can-t-I-have-the-option-of-assisted-dying>

I also admire her willingness to be photographed without a wig or a scarf, especially as I am still avoiding even looking at myself in the mirror without my wig, let alone letting anyone else see me.

Less is better

Five days after my last chemo session and I am feeling so much better than I was after the previous one. The 20% reduction in the dose of each of the four chemotherapy drugs seems to have worked in that I am not totally depleted in energy the way I

have been in the first week after previous sessions, eating is not such a problem, and there has been less discomfort. It's great to feel that life is worth living, especially in the first post-chemo week!

Going out to dinner with friends over the past week has also been really helpful. Not having to decide what to cook and choosing what I feel like eating at the last minute works well, and company when eating also makes a big difference.

So I think less chemo is better for me, as it seems to have given me the quality of life that I lost for the best part of a week following the first three chemo sessions.

Fourth chemotherapy session completed

At my pre-chemo session with Dr S on Tuesday I turned up with my usual list of questions. As I had spent several hours on Thursday in Acute Oncology having X-rays, more blood tests, and various other examinations and tests due to several days of having more pain in my digestive tract than usual, I wanted to check out a number of things about the results. All the tests I had there revealed there was nothing seriously wrong, and so the doctor there had been happy for me to return home.

The good news was that the pancreatic cancer biomarker (CA 19-9) had reduced from 17,000 to 9,500 which was a good sign. I also wanted to know where he thought the cancer might eventually spread to, as I needed to prepare for the possibility of not being competent to make decisions if it spread to my brain. He could not be certain, but said he would expect it to stay pretty much in my abdomen given my cancer

history so far.

Then Dr S raised the issue of his thinking it would be good idea to slightly reduce the dosage of all four drugs I was taking, due to how exhausted, depleted and dreadful I felt post-chemo. He described it as my wanting to roll into my coffin already. We talked about that. I do appreciate our conversations, as Dr S doesn't try and sugar coat his answers and is open and honest with me. When he doesn't know the answer to one of my out of the ordinary questions he tells me where I can get the answer, eg the cost of the chemo drugs.

So today I had my fourth chemo session with a 20% reduction of the dose of each of the three drugs, as well as a 20% reduction in the dosage of the capecitabine tablets I take twice a day. I had lots of support throughout the day from family and a very special friend. I lapped up their love and their willingness to visit me in the Oncology chemo day-stay ward.

Here's hoping that I will not feel so awful over the next few days.

Food and pain

After a really bad post-chemo week which included not being able to face the thought of food I have been grieving the loss of what was once an important part of my life – growing some of my own food, preparing and cooking meals and eating. I now have no appetite at all, I am never hungry no matter how long it is since I have eaten, and the mere smell of food cooking is enough to put me off the thought of eating anything. The smell of the neighbours' BBQs has me relocating to another side of the house.

To try and stem the weight loss I make and sip smoothies on and off all day which I fortify with the nutritional supplement the oncologist prescribed for me.

Basically my entire gastrointestinal tract now feels hostile to me from my cracked lips right through to the other end!

It doesn't help that any liquid or food I have is followed an hour or two later by a great deal of discomfort in my lower abdomen. The oncologist tells me this is most likely due to the presence of the cancer in my omentum. While the discomfort is something I can cope with most of the time, it sometimes crosses the threshold when accompanied by sharp pains which fortunately do not last long.

I have discontinued taking liquid paracetamol after realising that the short sharp stabs of pain disappeared after the second lot of chemo. As the pains I am currently experiencing are very irregular I am not prepared to be taking pain relief all the time, as it really isn't necessary.

However, now that I have entered the phase of feeling better I have now made it my mission to try and find a solution to my aversion to food. My willingness to continue with the chemotherapy regime I have chosen depends on it.

Third chemotherapy marathon completed

I approached yesterday's third chemotherapy marathon with less trepidation than the first two. For one thing I had had an extra week between what are supposed to be fortnightly sessions and after a wonderful week at Pukehina beach I was

feeling better than I have felt for quite a while. Secondly, the sharp twinges of pain that I have been experiencing for several months disappeared completely several days after the second lot of chemo. This meant I stopped taking the liquid paracetamol, so I had one less drug to worry about taking. And I also learned that the blood test I had had on Christmas Eve showed my post-chemo blood count was not as low as after the first lot of chemo.

At the appointment with the oncologist on Tuesday Dr S. told me that the disappearance of the twinges was a good sign.

I gave Dr S. a copy of the December issue of the AWHC newsletter and he told me he would give me a critique of the article I had written on Keytruda, Herceptin and PHARMAC. I told him I would look forward to his response. Throughout the appointment we kept getting hopelessly off topic.

I had a list of questions this time, and asked Dr S. if the four drugs I was taking were generic, as in off patent and therefore much cheaper. I also want to know how much they cost. He was not sure about whether they were all generic, but thought three were, and nor could he tell me what the cost was. He suggested I ask the pharmacy department next to the oncology day stay unit when I turned up for my chemo on Thursday.

I did this and explained why I wanted to know. Today I got a very welcome phone call from the guy I had talked to about my four PEXG drugs. They are all off patent, including the one I take in tablet form, capecitabine, which was originally made by Roche. So that was a bonus! So was the news that the cost of the four drugs for 12 fortnightly treatments was \$2,011. I had anticipated a much higher figure than that. Of course it doesn't include the cost of my fortnightly all day visits to the oncology day stay unit and the care from the nurses I receive there, and all the anti-nausea drugs and the nutritional supplements which Dr S. said are not cheap.

I had two friends visit me during yesterday's chemo session, and my eldest son turned up just before noon with a delicious lunch from Revive, which resulted in a number of the other patients there asking if they could put in their lunch orders. My son explained that his mother gets special treatment because she has to be there all day.

At 4pm my third son arrived to take me home. I felt really woozy and my body was once again in its post-chemo state of shock.

