

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?

[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.