

The continuing saga of the pain in the neck

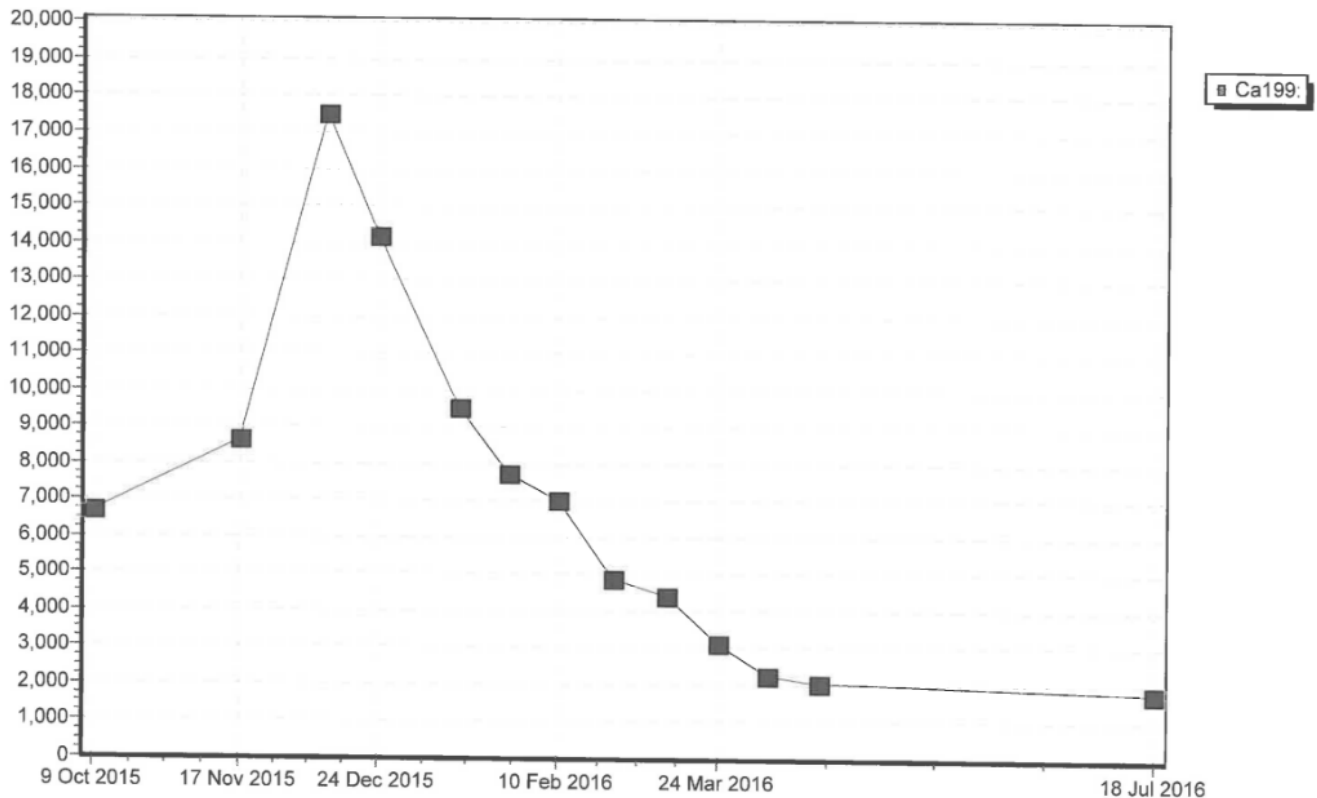
Unfortunately, the post-surgery plan for removing the cyst didn't work out, and I'm back to daily dressing changes for the next few days and every other day for goodness knows how long after that.

A swab of the wound on the back of my neck which my GP took five days after surgery revealed that it had become infected with a staph infection and I was put back on antibiotics. The wound was now oozing again and my ED doctor friend changed the dressing twice before recommending that I turn up at the Emergency Department at North Shore hospital on Saturday afternoon.

I arrived just after 3pm and after an hour I was seen by a nurse, and then an ED registrar who managed to convince a surgical registrar to come and examine the wound. Finally they decided to open the wound and remove some of the stitches which was done under local anaesthesia. I got home just after 7pm with a prescription for some more antibiotics, and a referral back to the surgical team who had performed the surgery 10 days ago.

However, I did receive some good news over the past week or so. The blood test I had the week before last revealed that my pancreatic cancer biomarker (CA19-9) is now down to 1810 (it was 2030 back in May). For the second time my GP printed out a graph of all the CA19-9 results since October last year and gave it to me. The increasing length of the plateau on the right hand side of the graph is very comforting. When I saw my oncologist, Dr S last week he was also very pleased, though a bit miffed that I already had the biomarker result. He likes to give me the good news, and I can understand that, given that he sees mainly pancreatic cancer patients, so he probably

doesn't get to give out good news very often.



My next appointment with Dr S will be at the end of October after I have had another CT scan. When I told him that I planned to celebrate still being alive on 9 October – which will be exactly a year since I was told I had pancreatic cancer – he said he would make sure that the scan was booked for after that date. I really appreciated that.

Following the cervical cancer screening conference that we (we being the Cartwright Collective) have organised for Friday 5 August, my next goal is to get to go on the week's holiday at Pukehina beach with several friends that has been planned for the week after the conference. Just have to hope that I can find a way of getting the two or three dressing changes that I will probably need while I am down there.

Shared experiences

The media attention in June and July resulted in some real gems. One of them is a fellow pancreatic cancer patient I am now in email contact with. He is in late 60s and like me was diagnosed with exocrine pancreatic cancer in October last year. His early experience of his cancer was very different to mine, but knowing he is out there, on the same path, and dealing with similar issues is a great comfort to me. We are travelling the same route at the same time which will have the same outcome. I no longer feel alone and disconnected from the “real” world, the world which is now for me divided into those who have a diagnosis of terminal cancer (or some other unsurvivable disease) and those who do not.

He referred me to a wonderful BBC series of three programmes called “The Big C & Me.” It shows shows how “there is no right way to cope with cancer – you just do.” All the people featured in the three episodes are ordinary people who respond to their cancer diagnosis and deal with their options in their own way. It is an honest, gutsy, heart-warming, and informative series that doesn’t gloss over the difficult bits. It even features several people with pancreatic cancer. I saw many of my own reactions and experiences echoed in the brave patients who agreed to be interviewed. I have started watching it for the second time because, having not had the chance to meet with anyone else with terminal cancer, this is the next best thing.

I have also just finished reading Jenny Diski’s book “In Gratitude.” My favourite part was section 2 – “Chemo and Me” – which is the second of the three sections of this fascinating book. It is a very witty and brutally honest account of her life and “patient journey” (how I hate that term – and so does Jenny – but she still uses it) written in the aftermath of her diagnosis in August 2014 with inoperable lung cancer. She was told she had two or three years to live. Again I found some of

my own thoughts reflected in her irreverent descriptions of her chemotherapy and radiotherapy palliative treatment, The description of the final stages of her disease and how it affected the control – or lack of control – over her body, are very confronting.

The next recently published book on my bedside table is Cory Taylor's "Dying: a memoir." Cory Taylor is an Australian novelist dying of melanoma-related brain cancer. She spent several years going through all the available treatment options, but has now come to the end of her life.

I am also keeping a close watch on the inimitable Helen Kelly's experience of terminal cancer –

<http://i.stuff.co.nz/national/health/82292705/helen-kelly-my-back-is-broken-and-i-only-have-months-to-live-but-im-pain-free>

These shared experiences offer me valuable insights and the sense of not being alone as I travel "90 miles an hour down a dead end street." (Apologies to Bob Dylan).

Surgery over and I'm home again

It all went really well at North Shore hospital yesterday and the surgery has set me free.

I was instructed to turn up at 8am. My sister got me there at 7am as there were no traffic problems, so we had plenty of time to sit around and prepare for what lay ahead. After half an hour or so we were taken into a room where I answered all

the standard routine questions that I have answered so many times before, and where I was asked to get into my hospital gear. I learned that I was second on the list, but would have quite a wait as the first person on the list was scheduled for a 3-hour operation. I was then taken into the pre-op room. I used the time to complete the Sudoku puzzles in the *Herald* and to catch up on some much needed sleep. Unsurprisingly, I hadn't actually managed to get much sleep the night before.

After signing the consent to surgery form around 11am, the anaesthetist turned up to go through the procedure with me. I asked him what drugs I would be given and he rattled off a list which included Dexamethasone, an anti-nausea drug, along with all the other drugs in the anaesthetic cocktail. At 11.45am I was wheeled into theatre. The operation took 20 minutes and the surgeon did what I hoped he would be able to do – excise the cyst and sew the wound up. So no need for a drain.

I woke in the recovery area around 12.45pm. I was given a very welcome cup of tea which was just wonderful after such a long period of not being able to eat or drink anything. I was also told I would be able to go home shortly. That was music to my ears, as I was preparing for a bit of a battle over my desire to go home. The news that the dressing on the back of my neck would need to stay on for 7 days and then once it was removed there would be no need for any more dressings also had me close to tears. The end of this saga, one of the consequences of all the chemotherapy I had endured, was in sight and I would soon feel whole again.

The staff were all just fabulous. They were very caring, seemed to be aware of my situation, and were sensitive to my needs. For example, I had actually been losing sleep over the prospect of my not being able to keep my wig on during surgery! While my hair has started to grow back I was still not ready for anyone to see me without a wig. I eventually decided that I would not wear a wig to the hospital, but would

bite the bullet and venture out of the house for the first time without it. The only covering for my head would be one of the many hats that one of my wonderful friends had knitted for me. So after I had put on the surgical head covering, I asked the nurses not to remove it after the operation as I wanted to keep it on until I could exchange it for my own hat.

Pathetic, I know. But the truth is I still have not accepted the body that I now inhabit. It continues to feel quite alien to me, and the loss of my hair has been a significant part of that feeling of alienation.

I arrived home around 3.30pm, lit the fire and settled in for the evening. A friend arrived soon after to look after me – her pre-planned visit turned out to be a necessary selling point in letting me go home straight after the operation – and my sons arrived later that evening with pizzas. Just what the patient had ordered!

[Booked for surgery](#)

On Monday 4 July I met first a registrar with a student in tow, then the surgeon and discussed my need for surgery to fix the cyst. The surgeon agreed to fit me in as soon as possible, but warned me that he may not be able to provide a permanent fix, and that I may need to stay in hospital overnight, something I am keen to avoid.

Following this appointment I have received a letter advising me that I have been scheduled for surgery on Wednesday 20 July. Fingers crossed that the surgery will be successful in completely resolving the current situation, and that I won't have to stay in overnight. I want to feel whole again.