

CT scan result

My fourth CT scan resulted in some good news. It revealed that the pancreatic tumours had not grown in size and had not spread any further. My last blood test showed that the pancreatic cancer biomarker (CA19-9) had reduced even further and was now down to 2030. Dr S. used the word stabilised and when I showed him the graph of my CA19-9 biomarker results my GP had produced and printed for me, he suggested I frame it. It has mirrored the results of the CT scans I had had over the past six months.

He recommended I make the most of the next couple of months which will not include repeated visits to the oncology clinic or fortnightly visits to the chemotherapy day stay unit. He said he would review me at the end of July and hoped to see me looking as good as I do now.

He then took a photo of me in my "I survived PEXG" t-shirt.

I told him my family had planned to tick one of the things off my bucket list over Queens Birthday weekend and we would all be spending three days at the chateau.

Yippee! Time for another little jig! And a virtual cartwheel! I am definitely going to get my year!



Our disconnected health system

A few days after my visit to Waitakere hospital's emergency department, I received a letter advising me of an appointment at 8.30am on Wednesday 18 May at Waitakere hospital. Thinking this was a prompt follow-up to my ED visit I turned up and after a few minutes I found myself in a room talking to the specialist who had expertly removed the basal cell carcinoma from the side of my nose in October 2014.

After experiencing some confusion about why I was there, I learned that this was not a follow-up appointment to my ED visit the week before. It was an appointment to discuss the referral for surgery to remove the sebaceous cyst on the back of my neck that my GP has sent in two weeks ago. The specialist did not know that following the visit to my GP who had advised me to go to ED should the cyst begin oozing, and having received the same advice from my oncologist Dr S. when things got worse, I had indeed turned up at Waitakere hospital the week before.

The specialist also did not know that I had been diagnosed with pancreatic cancer and nor did he know that I had just endured five months of very heavy duty chemotherapy. This felt very unsafe.

How can a doctor discuss options for dealing with a health issue with a patient when he does not have a complete record of recent and hugely significant health events in the patient's life? This is an utterly appalling situation. It relies on the patient being able to give an accurate account of the missing information once it becomes clear that the

doctor does not have a complete picture of the patient's current situation. And should the patient not be aware that the doctor doesn't have all the information he or she needs, what happens then? It doesn't bear thinking about!

I gave a brief summary of the events of the past six months to the specialist and described the history of my sebaceous cyst. I also admitted that I did not feel ready to be having surgery for the complete removal of the cyst so soon after finishing chemotherapy. Hospitals feel like dangerous places to me at the moment. And as difficult as having regular changes of the dressings are, these are preferable to being admitted to hospital for surgery. He agreed. He also said he suspected that the chemotherapy had contributed to the sudden inflammation and break down of the skin on the cyst.

I paid the parking fee and walked towards my car feeling tearful and utterly terrified at how disconnected the health system is. This is unsafe care and it is simply not good enough. But I am not sure I have the energy to write a formal complaint.

[Another hospital adventure](#)

For the past 50 years I have had a sebaceous cyst on the back of my neck that has continued to increase in size, particularly over recent years, but has never caused me any problems. However, it became inflamed after the last lot of chemotherapy and I mentioned this to Dr T. when I saw him at the oncology clinic on 26 April. He put me on a course of antibiotics. Ten days later I had finished the antibiotics but the cyst had become even more inflamed and was very painful. So I went and saw my GP. He prescribed a different antibiotic

and suggested if it got worse I present at the ED at Waitakere hospital. He also sent in a referral for me to get the cyst lanced and drained.

On Tuesday of this week after no further improvement, I emailed my oncologist Dr S. and asked him what he thought I should do. He suggested I go to ED at Waitakere and hopefully there would be someone there who would be able to lance and drain it. If not, I would be transferred to North Shore hospital, something I was keen to avoid.

I phoned my sister who took me to Waitakere hospital ED just after lunch. Despite explaining to those at the reception desk that I was a cancer patient and I had just had five months of chemotherapy, we sat in the ED waiting room for two hours while I contemplated the state of my immune system and tried to ignore the coughing of the few others also waiting. I also tried distracting myself by doing the Sudoku in the "Herald." Finally an ED registrar who is a friend of mine just happened to arrive to start work. She saw me and knowing that I was having chemotherapy she immediately ushered me and my sister into one of the ED rooms. She looked at the revolting mess on the back of my neck, and said she thought I would have to go to the North Shore. She then left and after a while came back with an ED specialist I knew who was quite confident that he could do the incision and clean up under local anaesthetic which he did, despite the cyst being so huge.

My sister and I had had several meetings with this man in the year leading up to the rather traumatic death of our brother in June last year, so we both knew him. But he looked quite shocked when I told him that I also had pancreatic cancer and was on my way out.

He competently lanced and cleaned out the cyst and I was home in time for dinner and was thankful that I could go to bed in my own bed.

The following day my ED registrar friend came round and changed the dressing – how is that for service? She was very pleased at how the wound was healing. The pain has gone and it is now just a bit sore.

I am so grateful that I just happened to get doctors that I knew and trusted, because I had spent days struggling with the prospect of turning up at a hospital ED when all I wanted was time out to heal from all the chemotherapy I had had and not have any more needles stuck into me.

Life after PEXG

Nearly four weeks after my 10th chemotherapy session and I am feeling so much better. My mouth ulcers have healed and my whole gastrointestinal tract has lost its hostility and painfully prickly feel. My appetite has returned, although I have to regain the sense of taste I had before I started chemotherapy. However, I think it is getting better, albeit very slowly.

It is also just grand to be off the fortnightly chemotherapy cycle and not having it dominate how I live my life. Over the past week I have been able to enjoy meals out and home cooking with friends and family. For example, I loved the dates scones made by and bought out to me by a retired gynaecologist when he came to visit me last week. He also bought good news about the book he has written on his time at National Women's Hospital. It is now looking hopeful that it will be published and I will get to read it before I die. As it's one of the few things on my bucket list it is a high priority for me, and part of my wanting to learn the outcomes of issues I have been involved with over the past few decades.