

Family birthdays

On Monday 23 November my youngest granddaughter turned four. On the Sunday prior to her birthday, her parents organised a small party with her daycare friends followed by a relaxed gathering of close family. The weather cleared and it was so nice to bask in the sun and be with all my children and five of my six grandchildren – as well as my elderly parents and my sister and her husband, and my niece and her family. However, for me these occasions are haunted by the question that now overshadows all family celebrations. Will I be at the next birthday or is this the last one?

On Saturday 5 December my youngest son turns 22 and another family gathering is planned at the lovely rural home in Ngaruawahia of my second son. We are all looking forward to it. While I am determined to be there when my son turns 23, I am very aware that I am revelling in each birthday, treating it as if it will be the last birthday of the person that I will be there for. It is such a bitter sweet feeling.

What ultrasound scan?

On 19 November I received a phone call about the appointment for my ultrasound scan. What ultrasound scan? The one your doctor ordered, I was told. Oh dear, the cancer must be affecting my memory because I don't recall Dr S saying anything about my needing to have another ultrasound scan. Playing for time I asked, "What doctor?" The one your GP, Dr G requested, was the answer. I quickly explained that I had had both an ultrasound scan and a CT scan in the private health sector, and was no longer in need of an ultrasound scan. I put

the phone down and stood frozen to the spot as the ramifications of what had just occurred dawned on me.

My GP ordered an ultrasound scan on 2 October. He wrote on it that he suspected I had cancer and that it was urgent. In the time it took the public health system to organise this ultrasound scan, I had had the scan plus a CT scan, seen the cancer surgeon at North Shore hospital, seen an oncologist at Auckland hospital, had a biopsy, chosen the chemotherapy regime, been to the chemo information session, and had a pre-chemo CT scan. Good grief! I actually didn't have that much time to waste on getting to the diagnosis!

How long would it have taken to get the CT scan I then needed in the public system, I wondered? Probably not before Christmas. It may have taken months to get a diagnosis, months I don't have.

Auckland Radiology, it was worth every cent!

[My new part-time job](#)

By the end of the chemotherapy info session on Tuesday it became clear to both my son and me that I actually have a new part-time job – as a cancer patient. It will start in earnest in a week or so. My first 8-hour chemotherapy session is scheduled for 3 December. On the Monday afternoon prior to that I have another appointment with the oncologist, and before I see him I have to have an ECG. Dr S. also wants me to have another CT scan before I start my chemo.

It was made very clear to all of us that seeing the doctor before our chemo session is not optional. If we don't attend the appointment with the doctor, we don't get the chemo.

At the end of the session we were all given personal packages which contained information about the specific chemo drugs we were each due to have. I learned that three of my four drugs would be given by infusion and the fourth, capecitabine also known as Xeloda, would be taken in the form of tablets. My own brief research had revealed that capecitabine appears to be mainly used to treat metastatic breast and colorectal cancers and that this drug is made by my arch enemy, Roche – which is going to make it a very bitter pill to swallow indeed.

More waiting

So my son and I rock on up to the Domain Lodge, arriving on the dot of 10am. We then spend 30 minutes waiting in the room where the chemotherapy information session is due to take place. It turned out that the letter was correct and the nurse was just ensuring that we got there early!

This is the second time this has happened. The letter from North Shore Hospital about my biopsy appointment said the appointment time was 10.15am. A few days prior to the appointment I got a phone call reminding me of the appointment which I was told was actually 9.45am. When we arrived – on the dot of 9.45am – we discovered that the letter was correct and the person who had phoned me was just ensuring we got there early! What my son overheard while waiting in the waiting room while I was having the biopsy, and what these disrespectful people at North Shore hospital didn't realise was that some people make a point of arriving 20 minutes or more before their scheduled appointment so they don't keep anybody waiting, only to find themselves waiting for nearly an hour before being seen!

On both occasions two of my sons took time off work to accompany me to these appointments which meant wasted time for them as well as me. These blatant lies about the actual scheduled time of appointments are completely unacceptable. This is about hospital routines without a thought for the patients and their support people. Shame on both DHBs!

They should all be required to read Eric Topol's latest book *"The Patient Will See You Now."*

Biopsy result

As I expected the biopsy result has confirmed the diagnosis of pancreatic cancer. No doubt, and no hope. I confess to having briefly indulged in a fantasy of a different scenario where I was an ovarian cancer patient with other options and more time. But I knew it was just that – a fantasy.

At the end of last week a letter arrived advising me of the appointment on Tuesday 17 November to attend an "orientation to chemotherapy" at the Domain Lodge in Grafton. Just as well I rang to confirm that I would be attending the two-hour session as the letter said 10.30am but the nurse insisted it was 10am. With four drugs to discuss I will need plenty of time.

I also hope to meet another pancreatic cancer patient there, so I can compare symptoms. The increasing lower abdominal discomfort and sharp twinges of pain puzzle me. I didn't know that having cancer would hurt like this. Or maybe this is something specific to pancreatic cancer?