

# Resigning from the Maternity Services Consumer Council

On Friday 18 March my resignation from the Maternity Services Consumer Council (MSCC) took effect. Over the following weekend the MSCC office was shifted into its new office space in Waipareira Avenue in Henderson. As I have worked as co-ordinator for the MSCC for nearly 25 years this was a significant day for me. However, I leave knowing that the list of things I wished to have completed before my departure has been done, and that the organisation has become a force to be reckoned with in terms of providing information to women about their birthing choices via our leaflets and website articles, etc, information that their doctors often don't give them.

I am very appreciative of all the support and encouragement I have had from so many people over the years, including all those who were members of the MSCC Steering Group, those who worked alongside of me doing most of the MSCC's financial and administrative tasks, thus freeing me up to writing a never-ending list of leaflets. It turns out that "*Choosing Where to Labour and Birth*" was the final leaflet I would write and it is leaflet I am very proud of. I hope that it will encourage women to push for change and realise that giving birth in high tech maternity hospitals interferes with the important hormonal processes of labour and birth and can have significant short and long term consequences for them and their babies. The revolution to reclaim birth is long overdue, and the rising rates of caesarean sections throughout the world are having a hugely negative impact on how we live, love and socialise.

Over the next few months, I plan to focus on my work for the Auckland Women's Health Council.

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## **Eighth chemotherapy marathon completed**

My eighth chemotherapy session on Thursday 17 March passed without incident. At the appointment with Dr S on the preceding Tuesday I learned that the pancreatic cancer biomarker (CA 19-9) had reduced from 4,890 to 4,400. I also asked about my haemoglobin blood test result as it has been suggested at the previous chemotherapy session that it was low and a blood transfusion was recommended. The result that Dr S had in front of him on Tuesday – 96 – was from almost two weeks ago. When I had another blood test a day later, the day before my eighth chemo session, it had dropped further to 90.

I know I am in the worst of the post-chemo phase now, but I am very reluctant to have a blood transfusion. I am so over needles. Even turning up for my weekly blood tests is a mission in itself. However, I have so few choices that I can't rule it out completely. I am not excessively tired or breathless, so I will wait and see.

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## **Celebrating my 66th birthday**

On Friday 11<sup>th</sup> of March I celebrated my 66<sup>th</sup> birthday. At the end of last year my children made celebrating my next birthday with me a high priority and we decided we would celebrate it by spending the weekend together at one of the West Auckland beaches. Given that there were 14 of us, we weren't going to

have a great deal of choice as to where we stayed but we wanted to all be together. My daughter found The Tower at Muriwai beach and last Friday evening we gathered in the most wonderful place imaginable with the most amazing views along the length of Muriwai beach you could wish for.

There were flowers and chocolate in balloons, cake, and lots of other yummy food, and wine and beer. And there was music. As usual there were also heated debates. My lot are, unsurprisingly, a rowdy lot with strongly held opinions on a range of issues. I had unintentionally sparked the beginnings of World War 3 at the beginning of the week by scanning and emailing to them the editorial about voting for a new flag that had appeared in the latest *Listener*. Fortunately, it had run its course by the time my birthday arrived. But of course there are always lots of other issues capable of sparking a noisy discussion.

Once the rain stopped on Friday, and the sun came out the weather for the rest of the weekend was great. After two breakfasts on Saturday morning we spent the rest of the day visiting the gannets, and then went down to the beach and watched the grandchildren play at the edge of the water, as well as watching the surfers who were making the most of the huge west coast waves. We then sat on the deck eating more cake, attending to emails (not me) and admiring the views before heading out for dinner.

It was a very special birthday in a very special place with very special people.



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## [Prolonging the dance with Mr D.](#)

Of course, there is a price to pay for prolonging the dance with Mr D. I was intensely aware of this in the days after last week's CT scan as I debated whether I was willing to continue with more chemotherapy. Not expecting such a favourable CT scan result had led me to swing towards contemplating giving up on the chemotherapy.

There are the weekly blood tests, the fortnightly appointments with the oncologist, and every second Thursday spent in the

day stay oncology ward. Then there are the side effects of the chemotherapy. Three more months of not enjoying food due to the loss of taste, the chemical taste in my mouth, the days when the grumbling stomach and lower abdominal pains after eating are difficult to deal with, and various other gastrointestinal pains – this is a big price to pay in my world. Then there is the feeling that my whole body has become quite alien to me.

I had two questions on my list this week, the answers to which pushed me firmly into agreeing to more chemotherapy. The first was with the information Dr S. now had about my tolerance of chemotherapy and the results of the CT scan, what was his estimate of my life expectancy if I chose not to have any more. His reply was 4 -5 months, maybe 6 months. The second question was what was his estimate of my life expectancy if I chose to continue and have another six sessions. His reply was about a year. So I opted to pay the price and continue.

Yesterday I had the seventh chemotherapy session, but managed to get them to hurry all the stuff that gets shoved through my IV line (no delays between them) so my son could pick me up at 3pm instead of 4pm. I asked for this first thing in the morning, having no idea of what was about to unfold in the room I was in a couple of hours later.

For the second time I witnessed what happens when a patient has a bad reaction to the chemotherapy drug(s). Only this time the woman was next to me with only an empty chair between us. It was a very scary thing, as the room filled with doctors and nurses, a screen was put around the woman, conversations are overheard (there is no privacy possible in the oncology day stay ward), me and the others in the room are temporarily relocated to another room, and the patient was eventually removed. Then we returned and the day carried on as if nothing has happened. No general words of reassurance for the rest of us. Fortunately, a friend had arrived just before this happened and her presence was very comforting as the drama

unfolded.

Surely I am not the only one wondering what happened to the patient, whether this could happen to any of us, and what the consequences are. I find this completely unacceptable. These scenarios were not mentioned in the Cancer Society's chemotherapy session that my eldest son and I attended. They should be, as it is not just preparing us for the possibility that this could happen to us, but also for dealing with the drama of having this unfold right in front of us.



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## CT scan result

Yippee! I'm dancing a little jig! Now it's a virtual cartwheel! It's unexpectedly good news. In fact, given the

circumstances it's quite miraculous.

After a fairly rough week I was not expecting very good news. But in response to the first question on my list Dr S told me that the pancreatic cancer biomarker (CA19-9) had reduced further from 7040 to 4890, and the other blood test results were in the normal range for someone on chemotherapy.

Then came the answer to the biggest and most scary question on my list – the results of the CT scan I had last Wednesday. The tumours have shrunk, and by more than 30%. This is known as a partial response and occurs in only 10 – 20% of people with my form of pancreatic cancer. Dr S showed us the images of both the November CT scan and last week's one on his computer – us being my eldest son, my ex-husband and me – and pointed out how the tumours in the omentum have also shrunk, making it less bulky than it was over three months ago.

So I will be rocking on up for another chemotherapy session on Thursday. I am going to get my year and a bit, and this wasn't my last summer! Amazing!

Yippee!! Another little jig and another virtual cartwheel!