

# A ménage a trois

There are now three of us in this dance. Two weeks ago Mr M joined us. Aware that his presence was inevitable, I finally agreed to his joining the party. Not everyone gets along with Mr M but Dr S. was sure that it was now time for us to meet. "You can't stay on Ibuprofen," he told me firmly. "It does terrible things to your stomach, and that's the last thing you need." However I was rather nervous and I wasn't at all sure what I would do if I was one of those patients who do not tolerate morphine at all well.

The first week was rather bizarre. During the day I kept seeing things that weren't there, and at night I would often surface from some dream to find myself talking very loudly about some important point I was trying to make. As I lay there struggling to wake up properly I found I couldn't get myself to shut up. It was all very weird and embarrassing. During the day I had a very dry mouth and felt very lethargic and tired. I also wasn't in the least bit hungry. And I won't mention the other common side effect. So of course I had to take another drug to cope with that.

Over Labour Weekend some of my family headed up to Mangawhai Heads with me in tow. It was good to be able to talk to my friend's pharmacist husband about my symptoms. He assured me that my body would start adjusting and in another week or so many of the symptoms would subside or disappear completely. I can report that he was right. I am no longer in danger of waking half the neighbourhood with my middle of the night rantings. And I am not seeing things that aren't there. The lethargy has also subsided.

But best of all – and after all this was the whole point of my introduction to Mr M – I am no longer in pain.

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## A fearful decision

I have decided to go ahead with three sessions of paclitaxel. I had forgotten that Dr S. told me that it is given in three weekly sessions and then the fourth week is the chemo-free week. My first session is on Friday 11 November.

It is harder to agree to the chemo this time round because this drug is one of the ones that can cause an adverse reaction in patients. As I witnessed two adverse reactions earlier this year while having my PEXG chemotherapy in the day stay unit that were not handled at all well, I am very nervous. For paclitaxel it is actually the solvent the drug is mixed in rather than the drug itself, but this is a technicality when it comes to my fear.

The second time it happened it was to someone in the same room as me, and this was even more frightening. If we had been prepared for this possibility either during the Cancer Society chemotherapy sessions that we are all encouraged to attend, or received some general reassurance after it happened then it would not have been so traumatic. We were all temporarily transferred out of the room and an hour or two later when we resumed our chairs the patient was gone and there was no mention of what had just happened. This simply added to the trauma. I lay awake that night wondering if she had survived and whether the other woman had as well. Fortunately Dr S. responded to my email and answered all my questions which helped reassure me. Besides, I wasn't on any of the chemo drugs he mentioned that sometimes cause an adverse reaction, so I tried to forget about it. Until now.

However, I have done my best to get as much information as I need, and I have started another list of questions for my next

visit to the oncology clinic on 8 November. I also have family and friends who understand and are prepared to be with me for these first three sessions.

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## CT scan result

On Monday 17 October I rocked on up to the oncology clinic to hear what Dr S had to say about the CT scan I had last week. With my eldest son and ex-husband in tow, I asked the oncologist to show us the images so I could see where the cancer had spread to. A few days previous to this, I had logged into my patient portal and seen that the blood test result for the pancreatic cancer biomarker showed that it was on the way back up again. At the end of July it was 1810, and last week it was 2,600. So the CA 19-9 blood test result had already confirmed my strong suspicion of what was going on in my body – the cancer was growing and spreading.

The scan result wasn't all doom and gloom. The tumour on my pancreas hadn't got any bigger, but the cancer on my left ovary had. And the report stated that the cancer was still largely within the peritoneum "with a moderate amount of peritoneal fluid and increasing peritoneal nodularity" since the last scan in May. Lungs, adrenal glands, liver and bowel all fine. So not too bad, as it hasn't spread too far.

Dr S. then offered me more chemotherapy, this time with a single drug – paclitaxel. We discussed why he thought this was a good option at some length. The unexpectedly effective response to PEXG I had – it kept the cancer stable – was a very good sign. It was after all responsible for my now being in the 20% of pancreatic cancer patients who are still alive after one year.

I am now in the process of making another very difficult decision. It would mean weekly visits to the chemo day stay ward, but the infusion would only take an hour or so, he said. It would not be an all-day experience like having PEXG. I would probably lose my hair again – so I face going back to wearing a wig. Sigh! The big question was my usual question – forget the averages, and give me a personal estimate of how long I have got if I decide not to have any more chemo (3 – 4 months) and if I do decide to give paclitaxel a go (6 months or more).

I mentioned the fact that the wound on the back of my neck had still not healed. Dr S. was suddenly very interested – he had not been in the least bit interested in my complaints about this at any of my previous visits. The reason was of course, that chemotherapy wouldn't be an option if I had an unhealed wound. He asked to have a look at it. He did this and said he thought it was healing very nicely and wasn't nearly as bad as he expected from my account. All very well for him to say as he is not the one having to have regular dressing changes. He said the wound was small enough not to be a problem as far as my trying another chemo drug is concerned.

I really would like another summer so I will probably give it a go. If I do go ahead I think I will undertake four chemo sessions and then review my decision.

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## [One year and still here](#)

On Sunday my family came for lunch, bringing food and bubbly and their love to celebrate the fact that one year post diagnosis I am still here, and looking good. The grandchildren brought their beautiful handmade cards and little bunches of

flowers. As a wonderful friend had visited the day before with a huge variety of flowers for me in recognition of this milestone, my lounge was filled with flowers and love. It was a very special day.

I thought about the contrast between the trauma of the diagnosis and then trying to work out how to tell my children the dreadful news on 9 October last year, with where we all are now. I am incredibly appreciative of all the love and support I have received from family and friends. The twelve months since then has had numerous ups and downs, and we have all learned lots, shared lots, and come through it together. Given the circumstances, the past year has increasingly felt like a gift.

Of course, my family being my family, we didn't shy away from discussing more serious stuff, like my new will. After a similar family gathering at the end of August which I called to discuss the drawing up of a new will, I had completed the legal side of things and sent copies of my new will to my five children. So there was a brief discussion of that and then what feels to me like the next hurdle – the CT scan scheduled for Thursday of this week. I warned my family that although I now have my pain temporarily under control I was not expecting good news.

We then talked about the next family events that we have planned, including my youngest granddaughter's 5<sup>th</sup> birthday in November. Still so much to look forward to!

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# Dealing with pain

This week I finally faced the fact that I needed to do something about the increasing amount of discomfort and pain I was experiencing. It was making living my life difficult and wearing me down. So I phoned one of the oncology nurses at Auckland hospital and told her the paracetamol I was taking wasn't enough to control the discomfort and painful twinges, and asked her what my options were. She told me about the three "antis" or as I choose to think of them the three aunties – anti-inflammatory, antispasmodic, and antacid. She suggested I pay a visit to my GP, so I went onto my patient portal and made an appointment for the following day.

I came out with two prescriptions – one for Ibuprofen, the anti-inflammatory, and the other for Omeprazole, an antacid. I declined the antispasmodic, Buscopan, due in part to the side effects. Besides I need to ease my way back to having to take pills on a daily basis. I was advised to continue taking the liquid paracetamol I have been guzzling my way through. So here I am back on drugs, and adjusting to the fact that I am unlikely to be able to cope without them from now on.

After just a few days it has made quite a difference. I still have some lower abdominal discomfort but it is very mild compared to what I have been experiencing over the past few weeks.

I also talked to an experienced pharmacist about what happens when these are not enough. I need to know a bit about the path ahead. He told me that there are a couple more steps to go before I am introduced to Mr Morphine. This was very reassuring. I had put off seeking help thinking that I would soon be on morphine. Now I can concentrate on getting the pain under control so I can start enjoying life again.