

# A tough week

It has been a tough week. But the chemo is not responsible for it being a tougher week than usual. Sure I have little energy on Mondays and Tuesdays, but that's not difficult to cope with. It's a walk in the park compared to PEXG.

Session three went without incident, apart from a mix-up in appointment times. As I headed in to the day stay unit for my 2pm treatment I received a phone call asking me if I was coming in. I was told I had been due in at 11.30am. I got out the letter and assured the caller that the letter I had been sent said 2pm. So my friend and I got a bit flustered at that point. However, once I was in there and all hooked up everything went well. I discovered that I was not the only one who had been sent letters with incorrect treatment appointment times. So I got my next three appointment times checked to make sure we were all in agreement with what the times were on their data base.

My difficulties coping with my week was caused by people. I really thought I had got passed the stage of people I know reasonably well trying to challenge or undermine the way I have dealt with my diagnosis and disease, and with the choices I have made about how I want to live the rest of my life. But I was mistaken.

It never fails to amaze me the boundaries people are prepared to cross when dealing with people like me who have chosen to accept their terminal cancer diagnosis and get on with living the rest of their life the way they want to. Making the most of each day, each week and whatever time I have left is not good enough for them. I should be chasing miracles, constantly repeating positive affirmations, living in hope, and adopting their philosophy of life. My choices obviously make some people very uncomfortable as was made very clear by the call I got on Monday. It took all my energy to deal positively with

the woman on the other end of the phone who seemed totally incapable of listening to anything I had to say.

I was confronted with another person two days later when I turned up to a meeting I usually turn up to. "Lynda, what are you doing here?" she wanted to know. Now this is not the first time she has asked me this. I replied that I intended to continue with the life I had been living prior to being diagnosed with cancer.

I cannot understand why this is so difficult for some people to comprehend or accept. I have few regrets, and I feel so privileged to have been able to have the kind of life and work I have had. Why would I want to give it up and charge off chasing miracle cures or sit around waiting to die?

She then grasped my shoulder in what may have been intended as a friendly gesture which was unfortunately followed by a comment said far too loudly (I was sitting with a bunch of 10 – 12 other people) "oh, you are all skin and bone!" I heard myself responding very defensively "Yes, well, I have lost a bit of weight since my diagnosis and treatment."

It isn't enough that these people may mean well. Their thoughtless behaviour can cause considerable distress. Fortunately, I am now linked up with some invaluable hospice services. My fortnightly art therapy sessions (no, I can't draw – these are one to one art therapy sessions, not art classes), and more recently my fortnightly upper body massage have helped me overcome most of the issues to do with my feeling alienated from my body that I have plainly laid bare in previous postings.

And my diagnosis has revealed that I actually have a great many friends who have rallied round me in so many ways and comforted and supported me. I don't have the words to adequately describe how thankful I am and how loved and treasured I feel.

Then there is my wonderful family who have also been there for me, each in their own way, all the while dealing with their own grief and distress at the prospect of losing their mother.

So as we prepare to celebrate the 5<sup>th</sup> birthday of my youngest grandchild tomorrow, I count myself as one very lucky woman. I am content – and happy most of the time – and I am looking forward to really enjoying the coming summer with family and friends.

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## Session two of paclitaxel

Session two of paclitaxel also passed without my experiencing any adverse reactions, but in some ways I found it harder to cope with this time. At one stage I felt close to tears as I contemplated the weekly trips to the oncology day stay unit that lay ahead, the insertion of the needle that sometimes goes smoothly and without any fuss and sometimes doesn't, and all the other activities such as weekly blood tests and three weekly trips to the oncology clinic that being back on chemotherapy involves.

It didn't help that the unit seemed really busy and/or short staffed, everything took longer than last week, and there were delays between the various processes. It was quite crowded when I arrived, the insertion of the needle was prolonged and has left a bruise, there was no privacy which became extremely disconcerting at various times, and I felt utterly exhausted by the time I left nearly four hours later.

Next week there will be no need to begin with a slow testing of the infusion with paclitaxel so it should be much quicker. I asked my ex-husband to explain to me again (he had done this

last week but I had forgotten what he said) how this drug worked as it is different to the four PEXG drugs I had earlier in the year. I find it helpful knowing how the drug is working to prevent the growth of the tumours.

As I did not have any severe side effects during the week in the lead up to the second session I am not expecting any this week either. But time will tell, and this time I will be paying much closer attention to any signs that my body is telling me "enough already."

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## Two celebrations

Over the past week I have celebrated two events. The first was my daughter's 39<sup>th</sup> birthday which I celebrated with a special lunch with her and her husband down on the Viaduct Basin in Auckland. I was able to enjoy my very favourite food – raw oysters. These are such a big treat for me. No matter how off my food I am I can always eat raw oysters. It was also such a lovely sunny day – my daughter tells me her birthdays are always warm sunny days no matter what the weather is on the days before and after her birthday. This year's birthday was no exception.



The second cause for celebration is that my first weekly session of chemotherapy of paclitaxel the following day went without incident. No adverse reactions. It took three hours as they proceed very slowly and very cautiously for the first two sessions due to the fact that one in four people experience an adverse reaction to paclitaxel infusions. Most are mild, but non-the-less I was very anxious. I wore my special "I survived PEXG" t-sheet to give me extra courage.

I also had three supporters with me for the whole time. It wasn't till the infusion was almost complete that I remembered that I had forgotten to ask one of my team to fulfil one very important task! Should I experience an adverse reaction, and once the situation was under control, I wanted one of them to go back and ensure the others having chemotherapy in the same room I was in that I was okay. By the time I remembered this, I had passed the test.

I am now home and feeling just fine. I had a fortified smoothie for dinner followed by a good night's sleep. If I can just ignore the results of the American election, life is looking pretty good right now.

I've also just added a new photo of me with my eldest son and daughter-in-law at the evening with Ben Goldacre to the blog post that I wrote about some weeks ago:

[\*An evening with Ben Goldacre\*](#)