A pink ribbon is draped vertically on the left side of the page, with a loop at the bottom.

# Chemo and Back Again

How I survived chemo,  
day by day

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Breast Cancer Nirvana



# Table of contents

Introduction .....	3
Wishing you all the best .....	4
What is chemo? .....	5
What is Herceptin? .....	6
My Chemo Diary 2011 .....	7
August, 1 month prior to chemo .....	7
September, starting chemo .....	12
October, chemo month #2 .....	25
November, chemo month #3 .....	37
December, 1 month post-chemo .....	58
2012 Chemo Diary .....	70
January, 2 months post-chemo .....	70
March, 4 months post-chemo .....	73
May, 6 months post-chemo .....	77
June, 7 months post-chemo .....	80
July, 8 months post-chemo .....	83
August, 9 months post-chemo .....	87
September, 10 months on from chemo .....	93
October, 11 months on .....	102
November, 11 months post-chemo .....	106
December, 1 year post-chemo .....	113
2013 Chemo Diary .....	118
February, 14 months on from chemo .....	118
March, 15 months post-chemo .....	123
April, 16 months post-chemo .....	129
May, 17 months post-chemo .....	136
June, 1.5 years post-chemo .....	138
Conclusion .....	143
About me .....	143
About Breast Cancer Nirvana .....	143

# Introduction

In coming to this e-book, I can only imagine that life has provided a cancer diagnosis for you or someone you care about, or you want to learn more about these complex things: cancer and chemotherapy (chemo).

This e-book is my real time chemo diary from 2011 to 2013 showing snapshots of life from when I found out that I needed to chemo (following my breast cancer diagnosis on 19 April 2011, mastectomy and breast reconstruction surgeries) through to post-chemo life in June 2013. My chemo diary shows the process of pre-chemo preparations, three months of chemo, a year of Herceptin and life after that.

I created this e-book as I wanted to bring together my experiences to help others by allowing people to see what chemo is really like, warts and all. By sharing my chemo diary, I wanted to simplify the information about chemo, help reduce the fear and unknown-ness, and show that chemo is doable and survivable with enough support and resources. I also wanted to show people what recovery is like and how things really progress post-chemo.

My hope is that your chemo experience might be a bit easier through learning from mine; what went well, what didn't and tips along the way.

wishing you all the best

I can honestly say that my chemo experiences (two separate times, over nine months) were some of the hardest times in my life. However on balance, chemo clarified my mind and made me a lot stronger. I had to fight hard for my survival and step up to be the survivor I needed to be. I am now cancer-free and well. And after chemo, I feel that I can do anything as practically everything in life is better and easier than doing chemo.

At one point, during my first chemo experience, I decided I would give up chemo (apparently many people feel that way). I was fortunate to have had an excellent Doctor who talked me through all the practicalities of this. I have no doubt that in 10 or 20 years, there will be far superior cancer treatments. But right here and now, chemo is the most effective treatment for some of us. My Doctor and I mapped out exactly how many days I would feel really sick. I started to realise that six months of chemo was really only 49 days of feeling really sick and investing in my life was worth that.

I hope my chemo diary helps in some small way as a support mechanism for you. It is important to know that the more support and quality relationships you have, the higher your survival rate. So accept quality resources, support and relationships around you.

I wish you all the best in your chemo journey; please feel free to drop me a line and ask any question or simply tell me about your experience at [breastcancer.nirvana@gmail.com](mailto:breastcancer.nirvana@gmail.com).

# what is chemo?

Chemotherapy (or chemo) is the treatment of cancer using anti-cancer (cytotoxic) drugs. The aim is to kill cancer cells while doing the least possible damage to normal cells.

Chemo is administered in tablet or intravenous (IV) infusion form. There are various chemo drug regimens such as AC or CMF. In 2011, I had CMF which is named after the initials of the three chemo drugs: Cyclophosphamide, Methotrexate and Fluorouracil.

Chemo is often given for three to six months but is tailored depending on the type, grade and stage of the breast cancer. I received infusions of CMF by injection each 21 days for three months.

The likely/possible side effects of chemo depend on the specific medications and each unique individual but may include: nausea, vomiting, changes in smell and taste, increased risk of infection, low red blood cell count, low platelets and increased risk of bleeding, diarrhoea, fatigue, sore mouth, skin changes and a few other things. Side effects are managed by your medical team but usually require prescription of other medications and rest.

# what is Herceptin?

Herceptin is a drug therapy that targets HER2+ breast cancer. HER2 positive breast cancer is a breast cancer that tests positive for a protein called human epidermal growth factor receptor 2 (HER2), which promotes the growth of cancer cells. In about 20 per cent of breast cancers, the cancer cells make an excess of HER2 due to a gene mutation. Herceptin specifically targets HER2, kills these cancer cells and decreases the risk of recurrence.

Herceptin is given by IV infusion every 21 days for 12 months (or longer). It is usually given along with traditional chemo but it may also be used alone or in combination with hormone-blocking medications, such as tamoxifen.

Herceptin is usually well tolerated, but it does have some possible side effects, such as congestive heart failure, allergic reaction, flu like symptoms, fever and chills, nausea and vomiting, pain and muscle aches, headache, dizziness, shortness of breath and lack of energy and strength.

For more information, see [www.breastcancer.org](http://www.breastcancer.org).

# My Chemo Diary 2011

## August, 1 month prior to chemo

### Never say never

AUGUST 6, 2011

Last week was a challenge. I seemed to have one step forward and two steps backward; it would have been better to stay still in one place the whole week. I think the last few months were just getting to me. Since April 19 and my breast cancer diagnosis, life has been an emotional roller coaster. And it does feel like a LOT all of a sudden.

Also, I was dreading going to the oncology appointment on Thursday. In the end, I went on my own as I thought that was just easier...

The oncologist was very thorough and helpful. She informed me that the tumour was HER2+ which means it is more aggressive. That sucks as it means that...we do need to be safe not sorry in the approach. So the oncologist recommended three months of chemotherapy called CMF (named after the initials of the chemo drugs used, i.e. cyclophosphamide, methotrexate and fluorouracil) plus a year of Herceptin.

Obviously, this is not how I saw my year heading AND I have always said, I would never do chemo again as the last experience was so awful (coupled with the fact that I still have some of the side effects from last time e.g. nerve damage). But as they say, never say never. After a headache, many tears and a bit of depression, I must say that I don't want to do chemo again. But that does not mean that I don't need it. After looking at logical criteria for decision making, my main deciding factor is that I don't want a regret i.e. in five years' time, if the cancer came back, I would really regret not having done chemo.

My oncologist said that CMF would be milder than the last lot of chemo drugs I had in the past such as AC (AC is a combination of two chemo drugs Adriamycin and Cyclophosphamide) plus Dosectaxel. I will not feel as sick or lose my hair completely. She also said that if it affected me too much, I could stop after one treatment and just do the Herceptin (though there is not much research on the Herceptin-only regime).

It is only 12 weeks I have to conclude. Four treatments, each of 21 days and that is only 84 days. With that in mind, I now want it over and done with as quickly as possible so I can have that side of things finished by Christmas.

The year of Herceptin is another matter entirely. It only takes half an hour to administer and is generally easily tolerated i.e. for me, just a dull headache and tiredness. The issue of finding veins is quite problematic too as...I don't have many good ones. It makes things harder than need be but is really common on this side of the cancer journey. All the blood tests and needles just cause so many issues.

So all of this stuff leaves me in another dilemma – work. So what will I do? Last time, I worked as much as I could during chemo and said I wouldn't do that again. So I guess I will take that time off but how I support myself financially is another question and for another week...I just don't know yet.

It has been an awful few days but I begrudgingly have to admit that things could be worse and that many people do have things a lot worse. However, I still am not okay about all of this and this is the challenge over the next weeks. Not that anyone is ever happy to do chemo but the goal is to be at peace with it at least.

Thanks to all the friends and family who've assisted me through this decision making journey.



## tip

Be clear on your decision making with chemo and other cancer treatments. I used quite a logical process including how I would feel in the future if diagnosed again. Also helpful, is looking at the length of the chemo period (e.g. 20 days of feeling unwell) in the big picture of your life.

## Pre-chemo

AUGUST 13, 2011

I have been advised that I'll be starting chemo in two weeks' time. There are a few things I'm doing to prepare:

- Move house (as I won't feel like doing that once chemo starts) as I am now on leave without pay. I'm moving in with my parents until I'm back working.
- Pre-chemo medical appointments a heart scan (it will be a baseline for to track if chemo damages my heart) plus a number of other medical, Plastic Surgery Unit etc appointments.
- Set up things in my parent's place so that life will be a bit easier e.g. get another TV organised.
- Finances I am also in negotiations with Human Resources to see if there they can assist me financially during the three month period. There is always a lot of cancer-administration (cadmin).

I have been going through a psychological process of accepting that I am about to do chemo. I don't know why it was such a big shock but it was. I think, from the first breast cancer, my biggest fear was doing chemo again and I just plain old didn't want to do it. However, not wanting to do something is not a valid reason for not doing it: e.g. teeth brushing or eating broccoli. Sometimes you have to do what you have to do.

I have been re-remembering how chemo went last time and lowering expectations of myself once treatment starts. My goal last time was a walk of half an hour a day (usually by the sea), to take my medications, to eat something and then lots of rest. So stocking up on DVDs seems the right thing to do. I will keep this chemo diary; thank goodness for this laptop. It's not a good idea to do much socialising as my immune system will be compromised but the odd social occasion will be good. It is as if I'm preparing to go in to a type of hibernation.

12 weeks doesn't sound as bad as three months. I will definitely be counting down the treatments and looking forward to life post chemo. And I certainly hope that these drugs (CMF plus Herceptin) will be mild! Thank Goodness I had my holiday earlier this year (Ireland and Wales for a month just before the cancer diagnosis).

tip

With chemo, your immune system is compromised and it's important to know on which days, you are most vulnerable and also to avoid exposure to sick people or public places with lots of people.

# september, starting chemo

## The First Chemo

SEPTEMBER 3, 2011

Two days ago, I went to Wellington Hospital for my first chemo. It is hard to describe but I will try.

A friend came to keep me company and getting to the appointment by 8.30am was a bit of a mission. However, we ended up with time for nice hot drinks before my appointment started.

First, a nurse weighed me and took me through to the day ward. There are eight lazy boy chairs in one section; I was first there so sat by the window looking out on to a vista of the city.

My nurse came over and put a hot wheat bag on to the back of my left hand; heat helps get a good vein (I had already drank 500ml before 8.30am to aid getting a good vein as sometimes, it's hard to find one). The nurse found a vein and put in a cannula quite easily (a cannula is needle with a tube attached which allows both injections and blood tests). This didn't hurt; it was a relief to get that sorted as it can often be tricky with a couple of attempts. She also took some blood and sent it to the lab.

She then hooked up perhaps a litre of saline so that I was getting lots of fluid. This is attached to a beeping machine (which administers over a set time) on a pole (so I can walk around and go to the toilet etc.).

After a few minutes, we went to meet my oncologist. She asked me if I had any questions and I signed a consent form. There wasn't too much to discuss as those discussions had already been held.

Another nurse gave me an anti-nausea tablet to stop me being sick from the chemo. I also had a prescription to fill later in the day with other anti-nausea

medications to take over the next few days (unfortunately, I am allergic to some of the anti-nausea drugs so it doesn't leave many anti-nausea options for me).

Then back to my chair and by this time, the other seats were filling up. The main thing my friend and I agreed was that all the others having chemo looked so healthy and normal. They do not look like unhealthy people at all which always reminds me of how weird cancer is. Some of the healthiest people I know have had cancer so it such an odd thing; there is such a mysterious element to it.

After waiting for the blood test to come back (everything was in normal range), the nurse started the chemo. Two of the CMF drugs ('M' and 'F') are like tubes which she just pushes through the cannula and took maybe ten minutes. I didn't feel anything.

The nurse then put a litre of the next drug 'C' on the pole which would administer over an hour.

I had prepared a chemo activity pack so I started reading magazines, doing a killer-Sudoku and doing a bit of sketching (my friend and I had a mandala each to colour in). I managed to eat a sandwich, a bit of yogurt and some nuts and grapes.

After about half an hour of the 'C', I started to feel a bit off with a sore nose and stinging eyes. My arm was also cold from the cold drug (some are kept in the fridge) so my friend heated up the wheat bag for my arm.

My friend helped me out with lots of chats, going to buy me a scone, heating the wheat bag and helping me around e.g. to the toilet. It is challenging for the support people as well as the chemo recipient so it will be good to have her thoughts on how the day went.

After that was finished, Herceptin was added which as a loading dose (bigger first dose) administers over an hour and a half. With that, I developed a headache and got very cold, shaking cold. I got a blanket and put my jacket on top of the blanket and tried to rest a little as my eyes were still sore. I felt a bit nauseous but wasn't sick. The Nurse gave me two Paracetamol for the headache.

At around a quarter past one, we left the ward and met my parents who took me home. It's around an hour's drive and I slept in the back.

Once home, I felt really weird; my headache was getting worse and I took some more Paracetamol. I lay down and then started feeling quite sick and was sick a couple of times. It was not good. The district nurse rang to check on me and told me to take more of the anti-nausea medication. If I couldn't stop vomiting, she suggested that I go to the After Hours medical clinic at Wellington Hospital (one hour's drive away) which was not a great thing to look forward to. I did manage to fall asleep for a while.

Later in the evening, I wanted to get out of bed but I couldn't stand the light or food smells. Eventually that eased a bit and I got up and had a few chats with my parents and on the phone. I went to bed, slept well and felt a lot better the next morning. This is probably enough for now.

## tip

- Having 500 ml of liquid before getting to the hospital, hot drinks, exercise and keeping warm all help the veins; this becomes critical when chemo depends on a good vein.
- Prepare your chemo activity pack the night before and get your prescriptions filled.
- Have one notebook where you list your side effects, questions and answers and medical results. Prepare your questions before you get to the appointment.

## Day six

SEPTEMBER 8, 2011

Well, it's hard to know what to say. This week has been really hard. Probably harder mentally than physically. Only at Day Five could I really talk and write about the experience.

I seem to be unusually sensitive to both chemo medications and anti-nausea medications (and there aren't a lot of anti-nausea medications left to try). N.B this is not the situation for most people; I don't want to scare you off chemo!

Chemo day was a trauma and it makes me teary thinking about it. Then, the thought of doing it again three more times feels overwhelming at this point (but there are 21 days between chemo cycles and this time really helps regrow the strength to walk back in to the hospital each time).

The drugs can cause depression but in a way, the diagnosis, two surgeries and now chemo have cumulatively just made me bone weary. It has been a hard year.

Up until Day 4, I had mild nausea and this has been managed with medication. Physically, I didn't feel too bad at this point. My skin has been strange and congested and my hair/scalp a bit sore. I have had headaches and I am not sleeping that well. Yesterday, I had a tummy bug and headache for most the day.

Last time I did chemo, I found out that it is common for people re-question their decision to do chemo after the first one. It is an assault to every system and makes you feel crappy... but then it is helping to save your life. I have re-questioned whether I need to do chemo 'again' and re-decided that I probably do need to persevere and just do it. That process has also taken up a lot of mental energy.



One of the worst things about chemo is not knowing how you will feel tomorrow or next week. And that with each chemo, the side effects usually intensify. At the end of x months, you can feel worse not better.

Most days, I have gone for a walk on the beach which has been uplifting. Last night, a good friend gave me a pep talk and I have received some fantastic messages from friends and family. I know that I have heaps of support but unfortunately, they can't do chemo for me. In the end, chemo (depending on your drug regime) still can be very challenging.



## One day at a time

SEPTEMBER 15, 2011

I wanted to keep this chemo diary so that I could record what this is really like. But then I started to censor myself when I felt that my feelings weren't positive enough! I have finally come full circle with the censor and am writing an entry with the glass partially empty. I don't have to be positive about doing chemo; it's more important to be honest.

### Where has the energy gone?

Two weeks on, the chemo medications and trauma of the chemo have affected my personality and it is changing before my eyes. My tank has only half as much energy in it as normal. Though invisible to others, my spark is fading. Things that I could have handled two weeks ago now seem like hills to climb. It has felt like a dramatic transformation as I am usually quite a cheerful upbeat person. I know this is only temporary but this is my reality right now and I don't like it.

I have realised that when chemo finishes, that is the time for being positive, looking at learnings from the experience and making lists of all the things to be done. But now... is the time for being with the experience; my experience. So feeling down and sick when I'm down and sick, and feeling good when I can. It is my job to do chemo and just get through it as best as I can.

When I am feeling ill and don't know how I will feel the next day, I can't really plan much in advance. It is a strangely levelling feeling to be reduced to living one day at a time. By that I mean that I am forced to live in the moment, taking one day or hour at a time. Living for one day and working out how I should fill it based on how I feel, what I can feasibly do and what will make me feel good. It is I guess a fantasy that we are doing anything else but that?

I am starting to feel more fatigue. Sometimes doing basic chores seems too much but I have small waves of energy where I do the dishes and laundry. Yesterday, I was feeling comparatively good. Today, I have almost no energy. Sitting

in a chair almost all day would be just dandy. My mind hasn't quite caught up with this and thinks that 'doing' stuff is better. So my mind and body are playing tug of war.

### Chemo sucks and it doesn't

Today is one week to chemo #2 and two weeks on from chemo #1. I would prefer not to be doing chemo but it seems a moot point as I am doing it. Shouldn't I have moved on from these thoughts by now? I have kind of but at the same time, chemo sucks. And then it doesn't suck as it's lifesaving. A great conversation in my head.

I am not forcing myself be positive about chemo. It is not pleasant and I don't want to be cheerful and positive when I am not feeling that way. My goal is just to get through it in whatever way I can. Plus try to do some fun things when energy allows. Sometimes, I do not feel that I have it in me to do chemo #2; conversely, I do feel I have it in me, just.

I emailed my oncologist to explain that the first chemo didn't go well and that we needed to do something different next time. She responded positively and told me that she would prescribe a new (super) anti-nausea drug (apparently, you have to fail with the normal anti-nausea drugs to receive this new one). I think I have a good oncologist (and it's great that I can email her) but I feel that I will be a guinea pig again as I don't know how I'll react with the new drug.

I am frustrated when nurses say "oh you are just nervous" or "just anxious". I don't know many people who would be blissful about doing chemotherapy. However, I recognise that all chemos are different (with varying levels of side effects; Some people feel absolutely fine doing some chemo regimes) and yes, I know that I am lucky to live in a country where I receive free chemotherapy.

It's funny, when you are going through cancer treatments, cancer the disease often takes a back seat as you focus on getting through the cancer treatments. To me, chemo is harder than cancer.

### What has helped me

I still love to walk on the beach. There is something healing about the turquoise waves and all those white shells. I have loved the sunny days (though I am not supposed to go out in the sun while having chemo) and equally loved the huge hailstorm on Tuesday. It looked more like snow.

I have had a few coffees with good friends who listen to my stories and then we chat about life and have a laugh. I feel normal at those times. And I potter on my laptop from time to time; working on the Breast Cancer Nirvana website has been therapy for me. I also did an art therapy session (funded through the local Cancer Support Organization) The art therapist is a fantastic listener and I come away feeling better about life. I went to see Jane Eyre the movie this week and really enjoyed it. I am meeting a few friends this weekend; these are friends that make me feel good and who are supportive. My Mum has been great, helping me whenever she can.

I have also recently befriended two gals (in their 30s) who are going through breast cancer too. It is so helpful to chat to them about medications, surgery, side effects and have a laugh at it all when we can. Last night, I went to a support group through the local Cancer Support Organisation. I met a group of young cancer survivors who couldn't be more inspiring.

I have needed cake some days and little treats (my inner shopaholic coming out). I bought myself a funky silver and black jewellery box from Trade Aid. It is bright and shiny and makes me happy to look at it and I love that it is a Fair Trade product.

I have asked friends and family for emails, texts, calls and coffees, especially in the chemo week. Any messages of support or inspiring stories are gratefully received.

## tip

Do as many fun things as you can and as energy allows. Going through chemo is one time in your life to spoil yourself and have as much enjoyment as possible.

Email your medical team. If they are happy with that, it is fantastic to be able to communicate and solve issues quickly without making a call or appointment.

Don't go out in the sun too much while receiving chemo; some chemo drugs may make your skin more sensitive to the sun.

## A Successful Chemo #2

SEPTEMBER 25, 2011

My second chemo day (22 September) was an absolute success in comparison to chemo #1! It went like this:

### Two weeks before:

- My oncologist and I had agreed on a new 'plan' for my second chemo, which I was happy with and included a new anti-nausea medication.
- My oncologist faxed the prescription through to my local pharmacy.

### Two days before:

- I picked up the anti-nausea meds from the pharmacy.

### The day before:

- At 9am, I went to the local Medical Laboratory for the pre-chemo blood test. This blood test is important so that the oncologist can check for a range of things but the main concern is the neutrophil level as neutrophil counts fall temporarily with most chemotherapy drugs. Neutrophils are the most abundant white blood cells in humans; they account for approximately 70% of all white blood cells.
- Unfortunately, I have a problem with veins and it took three attempts, two nurses, half an hour and a bit of distress, before anyone could find a vein (and blood).
- The night before and morning of the chemo, I took a prescribed anti-anxiety medication; this is quite normal for many people doing chemo as they feel pre-chemo anxiety.
- I prepared my chemo activity kit (magazines, coloured pencils and paper, Sudoku book, warm clothes etc.).

### D Day (or 'C' Day):

- I drank 500ml-plus before my appointment at 10am. This ensures the veins are plumped up. I also dressed extra warmly and wore gloves to keep my hands warm (which also helps the veins come to the surface).
- My Mum and I drove an hour to Wellington hospital and parked at the local Cancer Support Organisation. On the way, we picked up: several new magazines, flavoured water (as I am finding that water tastes strange because of the chemo) and hot drinks.
- At the hospital, a nurse weighed me and I was the same weight. Chemo drugs are given on a millilitre per kilo rate so they check weight each time (also chemo drugs can cause rapid weight loss or gain).
- I was taken into a room to meet with my oncologist. We discussed side effects from the last chemo and how the new chemo medications would work.

### Neutrophils:

- The oncologist advised that my neutrophil (white blood cell count) was 0.7 and the minimum for chemo is 1.0. She wanted another blood test to see if my neutrophil count had increased from the day before.
- The blood test result would come back during the chemo session and if my neutrophil count was too low, a drug to stimulate neutrophil production would be given by injection. Sometimes chemo is delayed until the neutrophil count increases (but I just want to get all this chemo over and done with).
- N.B. Chemotherapy kills fast dividing cancer cells. It also ends up killing some fast dividing normal cells in the body, like some cells in the bone marrow that maintain the supply of white cells in the blood. The stated normal range for human blood counts varies between laboratories, but a neutrophil count of  $2.5\text{--}7.5 \times 10^9/\text{L}$  is a standard normal range. Low

neutrophil counts are termed neutropenia. Neutropenia can be a side effect of chemotherapy and makes an individual highly susceptible to infections.

#### Chemo begins:

- I took the new anti-nausea medication (a pill) an hour before the chemo started plus another anti-nausea pill, which I'd taken last time.



- Then the same process as last time: inserting the cannula into a vein on the back of my left hand, the blood test (first) from the cannula, then a saline IV to flush out the veins and get me hydrated. (See picture.)

#### Chemo day:

- Then three different chemotherapy drugs (CMF) plus Herceptin. No neutrophil related injection was required as my neutrophil count had increased overnight.
- I felt a lot better than last time. I did start getting a dull headache so took some headache medication while at the hospital.
- We left the hospital around 2.30pm and I felt quite good (comparatively).
- That afternoon, I went to bed and slept. I felt no nausea or headache – just a feeling of being quite drugged.

Since then:

- For the first two days, I felt quite drugged and very little nausea.
- Side effects continue; I have terrible skin, sore hair (some falling out but not noticeable) and difficulty concentrating, I am more fatigued and am sleeping longer and longer each day.
- I am quite concerned about the neutrophil count and avoiding groups of people or anyone with a cold, and I am washing my hands compulsively
- I am feeling relatively upbeat though. This chemo was not a trauma and I know that I can do two more chemo cycles. In saying that, it isn't easy but it isn't as hard as last time. This is a huge deal and I am thankful for my fantastic oncologist who listened to me and really helped me.

tip

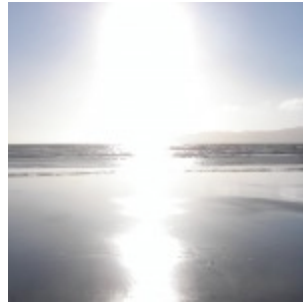
For those with problem veins, blood tests can be done once the cannula is inserted rather than the day before.



## october, chemo month #2

### A Game of two halves (challenges and triumphs)

OCTOBER 3, 2011



This last week has been a mixture of bits and pieces with a range of chemo side effects and allergies. Here is a quick list:

#### Challenges:

- **Sleep:** I seem to have forgotten how to sleep. The oncology nurse has recommended that I take half a sleeping pill on those nights. I don't like doing it but I need my sleep.
- **Chemo allergy:** My skin is awful; I have acne on my face to the point that I need to wear make-up when I go out. Apparently, it is an allergy to the chemo drugs; it might be too late to turn it around but I am taking an anti-histamine to lessen the effects on my skin.
- **Post-surgery stuff:** My new belly button (from the breast reconstruction) is maybe infected. The oncology nurse has given me a different cream to use for a week so will see how that goes.
- **Energy levels:** I need a lot more rest. I have been watching DVDs and trying to do Sudokus. But also doing a good walk most days.
- **Mood:** I do feel up and down. Part of it is the chemo drugs, part having cancer treatments and part, it's just been a jolly long year and I am over it! I can't wait to get my life back.

- **Anxiety:** Even though I only have two chemo cycles to go, it feels a really long way away. I am unsure as to when I'll be ready to work again and it plays on my mind. In the middle of the night, sometimes my brain just wants to work out why did I get cancer? And how can I ensure it doesn't come back?
- **Chemo brain:** I notice my thinking is blurring quite a bit; it's hard to concentrate and get things right. I need to delay any major decisions until my brain is back to normal. It is really hard write well but I am trying to keep a realistic chemo diary.
- **Immune system:** Right now, my white blood cell count will be quite low and instinctually, I just want to stay home and avoid catching bugs.

#### Triumphs:

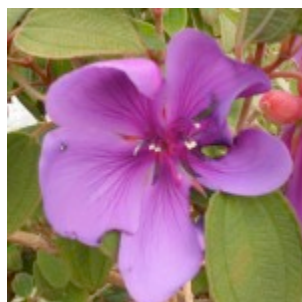
- **Success:** This chemo went so much better than the last one. Mentally, I know I can get through the next two chemo cycles. I'm feeling stronger and happier about how well the chemo went. There are some amazing anti-nausea drugs now!
- **No bugs:** I haven't had any colds or tummy bugs this time.
- **Support:** Staying with my parents, I am getting much better meals and support than I would have living on my own as I don't have much energy to cook.
- **Fun friends:** I have some good close friends who have kept in touch with me regularly and had some fun coffees and lunches.
- **Healing:** I am using bio-oil on all my surgery scars and they seem to be lessening.
- **A super nurse:** I have a new oncology district nurse and she is excellent. She rings me often and visited me this week.

- **Resting:** I am so grateful that I am not working as I am unsure how I could work without much sleep, with chemo brain and all the other side effects.
- **End of chemo celebration:** I am looking forward to finishing treatment and am thinking of planning a nice dinner out maybe 3-4 weeks after my last chemo.
- **Planning for the future:** It took simply ages to recover from the chemo I had in 2007. This time, I have the opportunity to really rest and friends say I shouldn't rush back to work and ensure that my job is not stressful.
- **Support group:** I went to a cancer support group through a local Cancer Support Organization. There were around ten people and we all just clicked. I think I have found some new best friends!

I am halfway through and next week have chemo #3.

## A Good Week

OCTOBER 10, 2011



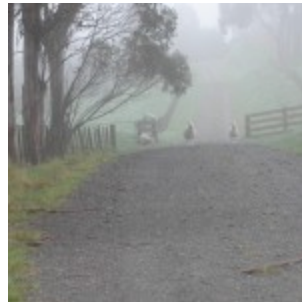
This last week has been pretty good overall:

- **Tuesday** – I drove to town to an Art Therapy session. The sessions are held at the Home of Compassion, a place I find inspiring. We did an art session on planning for my future post-chemo.
- In the afternoon, I went to a [Pink Pilates](#) session. Pink Pilates is subsidised one on one Pilates for those going through cancer. I have three subsidised sessions available and this was my first session. Apparently, my tummy muscles aren't too bad post-breast reconstruction surgery so that was good to know. It is nice to do some targeted exercise as Pink Pilates team are experts in Pilates for breast cancer patients.
- **Wednesday** – I caught up with a couple of friends and then went to see a movie, [The Orator](#). It was truly a wonderful movie full of amazing cinematography and I learned a lot about Samoan culture.
- **Thursday** – after so much activity this week, I crashed. I did not have the energy to do much more than watch a DVD and do a Sudoku. I did manage a 15 minute walk at the end of the day. I listened to my body and got the rest I needed as by the evening, I was feeling a lot better.
- **Friday/Saturday** – just normal days.
- **Sunday/Monday** – I'm at a cancer retreat in the beautiful Whangamata. I have had all the normal aches and pains this week but have got things more or less controlled thanks to my excellent oncology nurse and lots

of rest and good food. However, the elusive good night's sleep is still tricky to find. I have the third chemo this Thursday and then I'll be  $\frac{3}{4}$  through my chemo.

## Chemo no 3 – a kick in the tail

OCTOBER 17, 2011



Sheep in the mist

Well I am three quarters of the way through my chemo. Each chemo seems to have its own personality and this one had a kick to its tail. Last time, I had the perfect anti-nausea combo but this time, it wasn't quite right (although it was identical). Chemo is odd.

### The day before – Wednesday

I came back from the cancer retreat and stayed with my sister in law. We had a relaxing evening. I had this numb feeling in my hands and was tired (but I'm not sure if the numb hands were chemo-related or just fatigue).

### Chemo day – Thursday

On the day of chemo, I did feel mostly okay. I kept getting this pain at the back of my nose, kind of in between water up your nose and a headache. I haven't been able to get rid of it totally.

My neutrophil (white blood cell) count was 1.04 so I just made the minimum to have chemo.

My Mum, sister in law and nephew came to my chemo appointment so that was good company. We all coloured in a beach-themed mandala with aqua-coloured pencils (then used water to paint). It is a soothing thing to do while receiving chemo.

### Day one – Friday

I woke up feeling seedy. I had taken all the anti-nausea meds the night before and got up to take the morning's pills as well. I then went back to bed and forced myself to have a piece of toast with banana on it. I felt yuck; like a really bad hangover. When I finally got up, I drank lots of water, ginger ale (good for upset stomachs) and water with powdered bene-fibre to help ease my digestion. I didn't do much – watched a bit of TV, slept and replied to a couple of texts. I have been struggling to drink the required two litres a day so have started making up jelly for variety, it's easy to eat.

### Day two – Saturday

I felt quite a bit better. I took all my medications and had a proper breakfast. Then Mum and I went for a drive for an outing. We wandered around the shops and had a nice hot drink. In the evening, I started to feel unwell, like just about to throw up plus that nose pain came back. I took more anti-nausea meds and had more to drink. Then distracted myself for an hour or so before going to bed.

### Day three – Sunday

I feel a lot better again. But I still have this pain in the back of my nose, an off/on bleeding nose and indigestion. I just went for a walk to the beach and had a hot drink. Today, I feel like I can plan a little more for the week.

In the afternoon, I relented and called the oncology nurse as I was feeling awful. She gave me advice about what to do and take. She suggested taking Losec for the indigestion for a week, anti-nausea meds for three days longer than normal, and eye drops and nasal spray for the sore nose. I do feel like a pill-head though as I don't like taking these things. But hey, it's just about getting through the chemo.

A friend called and gave me a pep talk about health and priorities. That health is the priority and not to think about too many other things right now

“getting better is my full time job”. I have been trying to work out when is best for me to return to work and for how many hours. I’ll talk to my doctor next week and work out a plan. It is like being a psychic trying to predict the future.

#### Day four – Monday

I slept for 11 hours and still felt a bit wonky. I took all the new meds and then had an outing. I am feeling a bit better today but still have that sore nose thing. I am more tired than last chemo – sleeping during the day as well as at night.

Overall, I am feeling better that I am  $\frac{3}{4}$  through the treatment!

#### What has helped:

- Staying with my parents and being looked after
- Having healthy yummy meals cooked for me plus puddings at night like sago or tapioca
- Sleeping as long as I need to (sometimes ten/eleven hours)
- Walking on the beach (I saw a seal yesterday)
- Finding lots of new ways to drink liquid (water has an odd taste now due to the chemo) e.g. jelly, soy hot chocolate, cordials etc.
- Sketching, drawing and painting
- Watching TV shows like X Factor; I love the underdogs
- Texts, phone calls, postcards and emails from friends. I am very impressed that two friends have sent me seven postcards on their round the world trip!
- Hearing from my friends who are going through breast cancer treatment too (thinking of you!!)
- I’m looking forward to going to the Cancer Support Organisation group tomorrow and a lunch this week
- I’m starting to look forward and plan for life post-chemo. I can’t wait
- DVDs are great



- Writing this chemo diary. My Breast Cancer Nirvana website has been great therapy for me and I encourage people to keep a blog. Firstly, it is great therapy and secondly, it keeps people informed without you having to repeat the same information over and over
- Going on a cancer retreat
- Planning a post-chemo celebration dinner

## I turned a corner

OCTOBER 24, 2011



- On days five to six, I turned the magical corner – where I went from feeling totally crappy to just a bit crappy.
- I have learned a sleep lesson. One of the CMF chemo side effects is sleeplessness, but I have been trying to make myself sleep when I can't sleep. I had two nights where I probably got three to four hours sleep. I finally relented and listened to my doctor and oncology nurse (taking half a sleeping pill when I can't sleep). I don't like taking the pills but a girl has to do what she has to do to sleep. I have now had two nights of superb sleep and I feel so much better. On Thursday, I could hardly do anything as I was so tired and low from lack of sleep.
- This chemo cycle was different from the last one. I have had awful indigestion and tummy issues – and that pain in my nose was horrendous. The skin on my face and neck has been like a teenager with acne. It's amazing how that has affected me quite a bit. I wear foundation when I go out and have been wearing my hair down so you can't see too much.
- My hair has been falling out; not clumps but just everywhere. Luckily, my hair is very thick so it is not noticeable to others. I am lucky that with CMF, I won't lose all my hair.
- I have gained a few kilos. I am eating healthfully so think it must be the chemo as weight gain is a known side effect. It is a bit of pain though.

- I often feel good emotionally during the day but when I got to bed, all these thoughts come into my head. It has been a long long year and I am over it. It will be great to have the chemo over by Christmas.
- Energy levels. I have finally accepted that I can't visit my friends in the city (1 hour away). It just is too tiring. On Saturday, I met two friends half way to town (half an hour away) but even then, I was completely exhausted. So unless someone drives me, I will be home-based for the next month or so until my energy starts coming back. It is not worth the exhaustion that follows.
- Breathlessness. I am finding that I get puffed in doing minor things. It is a side effect from the chemo and Herceptin as I don't feel unfit.

What has helped me:

- **Getting sleep.** It is magic.
- **Talking to the oncology district nurse.** She suggested that I use a nasal spray and eye drops for my nose issue. It has helped a lot.
- **Talking to my doctor.** She is great!
- **For digestion issues.** 2x sachets of bene-fiber in food or drinks daily plus kiwicrush which I tried for the first time. It's good to have a variety of things to drink which also settle the stomach.
- **Going out when I can.** Wearing a flower in my hair or spot of happy colour makes me feel better.
- **Talking to my friends.** I feel normal life continues and plan bits and pieces for the future.
- **Walking** each day if possible.
- **Writing in my diary** and getting all the feelings out.
- **Fluids:** drinking 2 litres a day. Helps reduce side effects.
- **Reading stories** about other people who've survived cancer. It's inspiring and helps me see light at the end of the tunnel.

- **Support and messages of support:** I have heaps of support from my parents and friends. Thanks everyone.
- **Rest:** being able to rest is great!

## November, chemo month #3

### Nearing the end of chemo – if you can do chemo, you can do anything!

NOVEMBER 1, 2011

It seems remarkable but my chemo is about to end. I cannot wait! It feels like it has taken forever but in reality, only two months so far and it will be three months until the majority of the chemo drugs are out of my system. However, it does take longer to heal completely from the side effects and some stick around for a while, unfortunately. Also, I will continue with Herceptin for nine months.

I have been through a lot. Since the beginning of chemo:

- I have had side effects ranging from vomiting, nausea and a migraine. I have felt seedy more days than not.
- I have sore eyes and a sore scalp plus bleeding noses, headaches, indigestion and problem skin. My latest bugbear is a pain at the back of my nose which is hard to describe but there all the time.
- Lately I have noticed that my voice has gone weak and it's difficult to talk to people for any extended time.
- I get breathless when I do half an hour of walking. It is not about fitness but side effects of Herceptin and chemo.
- My energy levels have reduced by 50 to 75%. I find driving more than 10-15 minutes very tiring. People often say to me "you seem fine," but I am using up my energy with that interaction and then will rest later.
- Sleep: I have lost my ability to sleep on a regular basis without a sleeping tablet.
- My hair is falling out quite a bit but luckily will not fall out completely.
- Chemo brain: I find it difficult to concentrate or remember words correctly.

- Weight: I've gained about 5kg in the last two months from the drugs but also resting a lot.
- Immune system: I have an almost zero immune system. I have become phobic of germs and people with colds. My red and white blood counts are now the lowest they've been in years.
- I feel mentally tired as well as physically tired. I am sick of being sick; it is boring and depressing. Also, during the night, thoughts come about cancer and how the year has gone.
- Different chemos: I had a trauma with the first chemo and an almost miracle with the second one. It is amazing what drugs can do. The third cycle was in between; they all seem to have different personalities.
- Friends and family: some people have been in contact and others not at all. That is normal for this kind of thing and was easier this time around. Cancer is a sifting exercise with people in your life but it can be surprising who doesn't stay in touch.
- Work: I am so glad that I chose not to work. I would have had a much harder time if I was trying to work as well.
- The hardest part of chemo has been the side effects, especially from the first chemo. Physically, it was hard to tolerate and mentally, very difficult to decide to go back for chemo number two. In the end, I decided that I didn't want any regrets so just to have the chemo and move on.

#### What I am thankful for:

- An oncologist who listened to me and tweaked treatments to help me.
- An oncology district nurse who listened to every single side effect, reassured me that it was normal and then prescribed the right things to help me.
- A breast surgeon who has been vigilant with me.

- Some lessons learned from the last time I did chemo. I didn't have a mortgage this time so I could stop working during surgery and treatments, and rest and recuperate.
- Friends and family who have been supportive and been in touch. Thank you. Especially my parents for looking after me.
- That my treatments were free this time; Herceptin is funded publicly (but last time, we had to raise around \$67,000 for Herceptin treatment). And thank you to the women who advocated for free Herceptin until it became a reality.
- Writing these blogs and doing the website. It had been great therapy for me.
- The local Cancer Support Organisation for support and art therapy.
- That I was fit before I started chemo.
- That I didn't need six months of chemo.

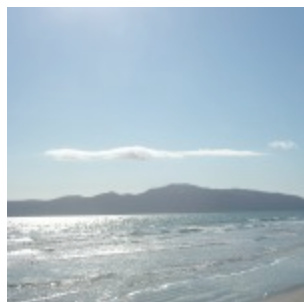
### Onwards and upwards

I now go on to a further nine months of Herceptin (by IV every three weeks), plus the final stage of the breast reconstruction, a small surgery in December. I will focus on recuperation and gradually rebuilding my energy and strength. However, Herceptin also makes me a bit tired and will slow down the recovery a little.

I am looking forward to getting my energy levels back and then gradually making some lifestyle changes. I am planning an end of chemo celebration. I have some girlfriends coming to stay in November so I'm sure we will think of something. In terms of the future, I honestly believe "if you can do chemo, you can do anything". So it'll be time to set some new goals for the future.

## The Last Chemo

NOVEMBER 6, 2011



A good day

It's amazing but I don't feel glad that it's over yet. I'm still a bit drugged up and feeling 'chemoed.' I'm sure I will in about a week's time.

It was quite a special chemo day. Though I wasn't looking forward to it; in fact, I started feeling nauseous the night before (all nerves!).

Mum and I drove in to the city and picked up hot drinks (to help the veins cooperate). We picked up a friend from work and then went in to the Blood and Cancer Centre at the hospital.

I went over to a chair, and waited for the nurse to insert a cannula (to have a blood test first). Normal blood tests are a nightmare for me as the veins in my arms simply hide. It is not fun playing hide and seek with needles and veins. But the vein on the back of my left hand is solid and used for a blood test plus inserting the chemo drugs.

After the blood test, the nurse connected up some saline by IV, then Herceptin. I then walked over with my IV pole and Herceptin to meet with the oncologist.

I met with the oncologist and went through side effects from last time and my list of concerns:

- Good news, I had a bone scan this week and I even though I have osteopenia (one step from osteoporosis), my bones have increased density since the last scan two years ago. N.B. As the first breast cancer



was estrogen positive (fed by estrogen), I have had to take hormone therapy to reduce estrogen in my body for the last four years. This has reduced my bone health to that of a woman two to three decades older than me. In a month's time, I will start taking another hormone therapy which will again reduce my estrogen levels. My oncologist also suggested ways to help with the side effects of the next hormonal therapy which I will start taking in about a month.

- The oncologist suggested that I take another type of steroidal nasal spray to help with the nose issue. It has been a right pain and only lessened a couple of days before the chemo.
- My oncologist said my skin would sort itself out in a month and gave me my schedule for medications over the next week. I have done a chart now to help me with my medications as it is hard to remember what to take and when.
- From Day One of chemo, there is Losec half an hour before breakfast to help with indigestion. With breakfast, I take two anti-nausea tablets plus an anti-histamine. I then use the nasal sprays plus eye drops. I take bene-fibre and kiwicrush to help with digestion plus before sleep, take ¼ of an anti-psychotic pill, an anti-anxiety pill plus anti-nausea and eye drops. After Day Four, I stop taking the anti-nausea, anti-anxiety and anti-psychotic medications! Though last chemo, I needed the anti-nausea tablets a couple days longer.

When I went back to my chair, sitting there was Mum, my sister in law, a friend and Father John Rae. [Father John](#) is a Catholic priest who is known for miraculous healing (he had been visiting another ill friend and popped in to the hospital on the way back). I am not Catholic but it is very calming being with him and there has been some documented cases of healing through him.

I took another anti-nausea medication and then the CMF chemo was administered. I had a dull headache so took headache medication plus the nose pain came up again. After the chemo and for two days after, I felt woozy and it was hard to walk in a straight line.

I then did a mandala drawing, as the colouring-in relaxes me during chemo, and we had some excellent magazines, hot drinks, snacks and ginger biscuits.

One of the Cancer Support Organisation volunteers talked to me about my website and was very encouraging.

So around 3pm, I headed home. Just relaxed and went to bed very early.

I have felt quite quiet and slow since then...but within a week, I will be feeling a lot better.

#### What has helped:

- Communication from friends and family. Thank you!!
- Lots of sleep, including afternoon naps.
- Drinking the mandatory 2 litres a day.
- The support of everyone around me.
- Reducing stress as much as possible and trying only to have positivity around me (e.g. cutting back on the news, too much info from my work and negative stories, especially negative stories about cancer).
- The new cancer support group I have.
- Generosity of people. I had a few gifts recently e.g. from Pink Pilates.
- Taking time to recuperate, not rushing around.
- Eating well and doing exercise (walking in my case).
- I did some sale shopping and found an excellent \$5 T-shirt.
- Doing a chart of my medications with timing.
- Not driving much at all.
- Keeping a notebook just for side effects, questions and conversations with the oncologist and oncology nurse.

So....within a few days, I will feel like celebrating. Two friends are coming to stay next weekend so that will be fun.

## I'm getting better

NOVEMBER 10, 2011



Chinese Lantern by Heather Carver

### Better, or is it a trick of the mind?

I am delighted to report that this fourth chemo has been less severe so far than the third one. Or perhaps my expectations were so low of this chemo cycle, that in reality the side effects are the same? I had a horrible feeling that the fourth chemo was going to be really hard...which was a trick of my mind. I am very relieved that I'm not feeling as ill as last time.

### Lessons learned from chemo

My experience with chemo four years ago was so terrible, that in a way, anything had to be better than that. But it is relative. My oncology nurse says that the chemo drugs this time are just as hard; it's just that then, chemo was new for me and I didn't really know how to 'do' chemo. In addition, I was working and tired all the time and had a lot more stressors (a mortgage to pay, Herceptin to pay for and six months of chemo instead of three). Also, this amazing drug Aprepitant wasn't available then.

This time, I have done chemo differently. I don't have to set the alarm clock to get up for work. I have treated chemo as if it was my job. My job is to do the cancer treatments and to get healthy. A friend suggested that I approach it that way and it is a good way to do it. I don't need to be at a desk achieving results while

feeling nauseous, confused, tired, chemo-brained, in pain etc. I am very lucky that I had the opportunity this time to do chemo differently.

### Chemo drugs

The chemo drugs themselves will be out of my system by December, but the side effects linger on. Last time I had chemo, I didn't feel 'right' again for three years but that isn't usual. Pre-chemo, I was in much worse shape with the shock of cancer, fatigue and life stress. This time 'the bottom' is not as deep so it will be a bit easier to rebuild myself. Chemo can still play tricks though; I still have some side effects from the first chemo (particularly nerve damage in my feet and fingers) and I am only half way through this chemo cycle.

### Side effects affecting me at the moment:

- Hair – it is really thinning now. No one else would notice but I can and it looks like I've had my hair cut shorter. Also, my scalp is painful with little sores all over my scalp.
- Dull headaches and feeling no energy.
- Chemo brain is becoming more of a problem. I am getting dates mixed up and have to pay careful attention to things I'm writing.
- Chills. Yesterday was day 7 and my white blood cells/immune system crashed (white blood cells go to almost zero for 7-14 days). When I went to bed, I had chills and was hoping that it wasn't an infection...but, I woke up okay, phew.
- The skin on my face is still pretty bad. I can't wait for that to clear up. A friend said that I looked like I had chickenpox.
- I am having odd bladder issues as the chemo irritated my bladder.
- I am really tired and sleeping (aided) about ten hours plus a night. I am hoping that in December, I will start to sleep properly.
- My nose is still irritated and sore; eye drops and nasal sprays are helping.

### Invisibility

Sometimes I find it funny that people look at me and think that I am completely well. Sometimes it bugs me though. Chemo affects everything on the inside and only a couple of things on the outside. Someone from work once told me that they expected that I would be 100% and back to work after the last chemo. It is quite deceptive that some of the people that I know with cancer, doing treatments, doing chemo ...look amazing. They are healthy people in practice and on the outside too. It's just the cells are doing strange things.

### Seeing the year in perspective

I am starting to be able to see that chemo is over. It is sheer relief; I can't imagine what doing six months would be like for me, it would have done my head in. The first cycle was awful. The second was much better. Third, not so good and fourth, better than the third.

I am not yet celebrating completely but trying to plan a few things. I am starting to actually integrate the experiences of the year; there have a couple of traumas this year and I haven't had time to process them as I've been busy 'doing' surgery and chemo. There is a lot to think about and move on from and I now have a bit of space to do that.

If cancer hadn't struck, right now I would have been working and living in Papua New Guinea. Life had really been shaken about this year.

### Where from here:

- I continue with Herceptin by IV each 21 days for nine months.
- I will go on a hormone therapy for five years.
- I will have heart scans each 12 weeks (to check that Herceptin doesn't harm my heart).
- There will be regular check-ups with my doctor, oncologist, breast surgeon and plastic surgeon.

- I have my third and final breast reconstruction surgery in December.
- I will wait until the chemo is out of my system and then I will start to plan... but the tentative plan is to go back to work in the New Year part time.
- I am focusing on eating well, resting, gentle exercise and rebuilding myself back to the new normal.

#### What has worked for me:

- Meeting others through the local Cancer Support Organisation.
- Treating cancer and chemo 'as a job' (and not having to do other work at the same time).
- Taking all the medications recommended for each chemo and side effect.
- Doing a table listing all the different medications and time of the day to be taken.
- Spending most of my time at home (so not to pick up infections with a compromised immune system).
- Seeing cancer as a blip in my life and also seeing it as an opportunity for transformation.
- Keeping a blog; it's great therapy and for those who've read it, they've been able to better understand what breast cancer is all about.
- Staying with supportive family – it takes a whole lot of physical stress off you if you have someone to help.
- In general, take someone with you to medical appointments.
- Reading inspiring books. I can't handle anything negative or challenging at the moment.
- Art therapy and Emotional Freedom Technique (EFT) – it's good to talk and deal with stuff so I don't keep it in my head.
- The local Cancer Society is fantastic; their groups, courses, information etc.

- Walking on the beach.
- Having slow days – time to reflect and let the nervous system have a break.
- Getting lots of sleep, however you get there.
- Talking to the oncology district nurse regularly.
- Sketching while having chemo. It is a fantastic distraction and relaxing on a full on, challenging day.

tip

If you have issues with medical professionals not acting appropriately, talk to their supervisor or another health professional immediately. You do not need to experience sub-standard care.

If you have chills or are really cold, take your temperature and contact a nurse or doctor. Do not wait until things get worse.



## Chemo Diary 14 November 2011

NOVEMBER 14, 2011

I am amazed but I am feeling quite good. A lot of the side effects from just a few days ago have faded a bit. I am not sleeping too well but a lot of the physical side effects are reducing. I am relieved as I thought the last chemo would be huge. I had a great weekend with two good friends staying and that gave me a boost too. I'm tired today but will just take time to get my health back.

## Moving into the Post-chemo phase

NOVEMBER 18, 2011



### What is fatigue, what is nausea – what is what?

#### Nausea

This week, I have been having trouble reading myself. On the weekend, I was feeling good. Then Monday and Tuesday, I felt odd – out of sorts and in the end, it was nausea. I didn't work it out until I threw up; an 'aha' moment. Then I took an anti-nausea pill and of course, felt better.

#### Fatigue

Fatigue plays tricks on the mind as well as body. On Monday and Tuesday, I was so tired that I hardly moved from the couch, particularly with a bleeding nose for most of Tuesday and an almost zero white blood cell count this week. I haven't really felt like doing anything and having a shower felt like a big task.

To me, fatigue is when I wake up and think is there anything I absolutely have to do today as I feel knackered and can't quite make myself do things. I have been literally trying to will myself to do tasks. Can I walk to the beach? Not right now, but maybe later. Can I drive to the shops? Maybe tomorrow. Okay, I'll just sit on the couch for now.

### Chemo brain

I have been getting dates and times mixed up a lot; missing appointments, reading my diary dates incorrectly, getting birthday dates wrong and writing things in my diary on incorrect dates. I am only glad that I am not making these mistakes at work. I hope this sorts itself out soon.

### Reality check

I rang the oncology nurse to discuss the bleeding noses and she tweaked my medications. She went through my blood count history and also gave me a reality check: a few days back, I had chills during the night but didn't have a thermometer handy. I just soldiered on and luckily was able to get to sleep and woke up without an infection. The nurse told me that I should have a thermometer with me, and to ring a medical professional with any raised temperature. If I had an infection, it could have been life threatening (with almost zero immunity). "It's only life and death," she said.

Later in the week, I started to feel that life might be normal again. I have had a bit more energy.

## **The post-treatment phase**

### Mental health

Depression is very common with cancer and post treatments. There is a lot that goes on – shock of diagnosis, thinking life and death, and traumatic operations and treatments. But I don't feel depressed. I just feel flat and in limbo.

### Post-chemo: the next phase

I am struggling a bit with movement into the next phase: recovery. I am not ill but I am not well. I am stuck basically in convalescence.

There is a nagging feeling in my mind that I need to be productive and 'when will I be going back to work anyway?' In reality, I have just got to see how I

feel week by week. Especially when physically, I try to 'do' things and can't find the energy to do them.

I am coming to the realisation that even though the majority of my cancer treatment is over, I still need to take some time to simply rest, eat well and get better. Actually, I have another nine months of Herceptin to go plus a small surgery in December. It is not like I am exactly doing nothing. But perhaps doing nothing is actually okay.

### Day by day, the new job

My job has moved from 'doing chemo' to 'doing recovery'. I am working out what the job description looks like but I think it is something like:

- Work out how much energy I have each day and plan the day accordingly
- Eat lots of fruit and vegetables
- Drink lots of water
- Get outside and do a walk or gentle exercise
- Get help and support for the post-treatment phase including treatment of side effects
- Rest when tired
- Keep my mind positive and stress minimal
- Talk to supportive people

### What has helped this week:

- Having a friend and cousin to stay this weekend. Talking about inspiring projects for the future.
- Realising that my job description has changed from 'doing chemo' to 'doing recovery'.
- Planning my days better based on energy levels and cancelling quite a few appointments as I wasn't feeling up to them.
- Writing each day.

- Sleep hygiene – bath, book and bed. Getting into a new routine to wind down for a good night's sleep.
- Ringing the oncology nurse to talk through blood counts, bleeding noses etc.
- Talking through being in limbo stage with people who've been there.
- Doing some gentle exercise.

## The first of many Herceptin treatments

NOVEMBER 27, 2011

This week has been the usual pick'n'mix of bits and pieces. I was feeling quite good on Monday but I think wore myself out doing some writing. I woke at 3.30am on Tuesday with a migraine and luckily had some good migraine medicine to turn that around in a couple of hours. I felt really tired on Tuesday (post-migraine) but had already booked Pink Pilates which is a 45 minute drive each way from here. In the end, I decided to go (as I had cancelled last week when I wasn't feeling very well) and it was excellent and I got a lot out of it.

I was knackered on Wednesday and then started to get pre-hospital nausea and anxiety on Wednesday night and Thursday morning prior to going to hospital.

One piece of good news; I noticed that my skin has cleared up almost completely and there are no more sores on my head. My scalp is still a bit sore but not too bad. I think I have lost nearly half my hair but because my hair is long-ish and quite thick, no one else would notice. But it is falling out everywhere.

### Thursday: Herceptin appointment

The oncologist and I discussed a few things:

- Sleep, my inability to sleep properly is due half to the chemo and half to just everything that has happened this year. In late December, I should notice my sleep improving.
- Bladder irritation is normal but it will start to turn around soon when the chemo is out of my system.
- Fatigue. Some days I do not feel like doing anything, just sitting and staring in to space or watching DVDs. And then other days, I am able to do a few things. Sometimes I overdo it on the good days and then pay for it with worse fatigue the following day. If I drive or go in to the city, I need at least one rest day afterwards.

- I do use will power to do exercise most days (I have started doing a bit of biking which is good for fitness and learning balance again after the stomach surgery).
- I am having the 12 weekly heart scan next week (to check for possible heart damage from the Herceptin). If there is heart damage, then the Herceptin will stop. Last time I did Herceptin, I didn't have heart damage during the 12 months of Herceptin so I'm hoping that this year will be the same.
- I pointed out that the fourth chemo cycle was better than the third one. Yay.
- I will be going on an Aromatase Inhibitor (hormone therapy) for five years called Exemestane. This hormone therapy will weaken my bone health. I just had a bone density scan and I do not have osteoporosis but I am the step before, osteopenia. The oncologist encouraged me to have dairy in my diet. Also there is an annual injection I can have to boost the bone density.
- Statistics – with all the treatments I'm receiving, I have an approximate 94% survival rate over five years.
- The chemo will be in my system for around three more weeks. Then after that, side effects will gradually disappear.
- I told the oncologist about my Breast Cancer Nirvana website and she was supportive. She told me about an episode of Gok Wan's *How to Look Good Naked* that was very inspiring where Gok helped a young breast cancer survivor.

### Herceptin

I was feeling a bit nauseous just going to the chemo ward (all those hospital smells). After having the Herceptin, I have been feeling seriously crappy for nearly

two days. The side effects are meant to be a lot gentler than for chemo generally so I didn't expect to feel like that.

My feet are aching a lot; I have had nausea, a very painful nose, extreme fatigue, a metallic taste in my mouth, my skin has broken out again (but not as bad as with the chemo) and a feeling like I have a cold. Just when I felt that I was getting better from the chemo... Next time, I'll take an anti-nausea tablet for that day. By 7pm that night, my nose had more or less stopped hurting. It was lovely and sunny so I went for a walk on the beach. It was very healing.

I thought the side effects were mostly in my head but read more about the side effects online. The most common side effects associated with Herceptin in patients with breast cancer are:

- Infections, fever and chills
- Nausea and vomiting
- Pain (especially muscle pain)
- Headache
- Dizziness
- Shortness of breath
- Very low blood pressure
- Rash
- Lack of energy and strength – fatigue
- Diarrhoea
- Increased cough
- Low white and red blood cell counts

### Saturday and Sunday

Saturday, I was feeling a lot better but overdid it with some fun outings. So Sunday, I was feeling very tired and quiet. One positive is that I slept without half a sleeping tablet for the first time in a couple of months on Saturday night.



## Monday

Today, I realise that even though I had just Herceptin, there is still chemo in my body which has made this Herceptin treatment a challenging one. Hopefully, the next one will be easier and at least, I will know what to expect. I also talked to the oncology nurse and she thought I probably have oral thrush (from all the medications I've taken). She is looking in to a new anti-nausea medication for me to use next time.

I've been feeling a bit overwhelmed by the prospect of another nine months of cancer treatment. It feels like a really long time and just when I start to feel better, I get a new onslaught of one drug or another. Today, I am feeling physically better and feel like I can do this!!

## What has helped me:

- My sister in law taking me to the hospital appointment (makes it a bit easier to have someone there).
- Having an excellent oncologist that I can communicate easily with. Same with my oncology nurse.
- Planning some fun outings with friends.
- Talking to people going through similar things.
- Writing and talking about what is happening for me.
- Walking on the beach or a gentle bike ride. Even when I'm really tired, it gives me a bit more energy and an up feeling.
- Resting a lot but aiming for an outing each day.
- Supportive messages from good friends and family.

# December, 1 month post-chemo

December 2011

DECEMBER 3, 2011



I finished chemo around four weeks ago and now have nine months of Herceptin left. I had the first Herceptin last week and felt quite ill for a couple of days but am coming right. Other chemo side effects are gradually reducing but it is still a bit haphazard and each day, I'm not quite sure what to expect. However, I am feeling physically a lot better and have been biking or walking most days. It is good to be feeling a bit more energy and fewer side effects.

## A long time

It is daunting to have another nine months of Herceptin to go. At least it's free this time, but it is feeling like this is all taking such a long time. A part of me thinks that life 'proper' won't start again until all the Herceptin is out of the way as it's going to be hard to focus – then stop and start – and go through cycle after cycle, until September next year.

## Limbo

It is a bit like limbo land as I'm not ill anymore but I'm not better. It's hard to plan work, holidays and social events. I still don't feel there is enough energy

reserve there to commit to many things. Resting is sometimes harder than it sounds but the couch is my best resting place.

### A Giant To Do List

Now that I am feeling a bit better, I can see lists of tasks that I have put off since June. It's been a bit overwhelming and I have been feeling quite anxious about the lists. I have done these giant tables of lists...it is a bit ridiculous really as doing one or two tasks a day is enough.

### Hormone therapy

I started taking Exemestine, a hormone therapy, this week which I will take for up to five years. I am wondering if that has been making me feel a bit anxious and headachy re: the 'to do lists' above.

Exemestine is used to treat hormone-receptor-positive breast cancer as some breast cancers are made to grow faster by the natural hormone called estrogen. Exemestane is also used to help prevent the cancer from returning (for me, I have been told that it reduces local recurrence by about a third). Exemestane decreases the amount of estrogen the body makes and helps to slow or reverse the growth of these breast cancers.

It is like taking the opposite of Hormone Replacement Therapy (HRT), instead of adding estrogen, it is taken away. Side effects include headaches, hot flushes, hair loss, joint/bone/ muscle pain, tiredness, unusual sweating, nausea, diarrhoea, dizziness, and trouble sleeping. However, some people do not have any of these side effects.

### 'Cancer'

I am starting to really process that I have been through cancer and cancer treatments this year. I haven't really been able to do that fully until now. I am taking advantage of the cancer support services and doing a bit of writing.

### Third breast reconstruction surgery

I have been advised that this will be delayed until next year. I am okay with that (as long as it's not too far away) simply because I am 'hospitalised out'. I am very happy not to go back into hospitals if I can help it.

I had a post-treatment appointment with the local Cancer Support Organisation nurse. She gave me a lot of nutrition and other information and we talked through lifestyle changes recommended to prevent recurrence.

Overall things are getting better. I have Herceptin again next week and this time I have the appropriate anti-nausea medication so that is good. I am sure that this cycle will be better as I will have less chemo in my body.

I am looking forward to Christmas and seeing friends and family. The weather is heating up with lots of blue skies so that is promising.

## Leaving Chemo Behind

DECEMBER 12, 2011



### Chemo

Well, now that the chemo medications are disappearing from my body, some of the side effects are too and I am so happy about it:

- My skin has cleared up a lot and my hair/scalp has stopped hurting.
- Chemo brain, I am thinking a little more clearly (but not to normal levels and not remembering things very well).
- Interestingly, my hair is still falling out everywhere but it is not noticeable to others. Generally, most of the side effects are not visible to others.
- I still am not able to sleep well at all. It is starting to distress me but my medical team say not to worry about it. Someone gave me good advice about playing sleep CDs or talking books so I will give that a go. I definitely don't want to get back to work until I'm sleeping properly.
- Fatigue: I am noticing that it's best not to do too many outings. If I go out, I am tired that day and all of the next day. So I have to constantly do calculations of what is worth doing and worth paying the price for energy wise.

### Hormone therapy

The hormone therapy is causing a few teething issues with anxiety, feeling jittery a lot of the time. I talked to the oncology nurse and apparently it will calm

down in time as my hormones rebalance. So again, nothing to worry about but not a pleasant feeling. My feet have swollen up a size as have my ankles.

### Herceptin

Herceptin is this week. I think it should be a lot better and have the anti-nausea medication here to take. Fingers crossed.

### Work and finances

Not working has many advantages but I am starting to notice a certain lack of money, e.g. when I had my car service, so I hope to have some income coming in in a couple of months.

I am at a point when I can start to think about career, well a little bit. I worry that cancer is seen as a risk factor in the workplace and realistically, it is in the sense that I cannot be there 100% of the time. I will need to ensure that I work for a supportive manager/employer and that I don't over-commit initially. There is in the plenty of time in the future for work. Now is the time for resting and recharging.

### Fitness

I have been for a walk or bike ride every day for the last month and I am starting to feel my fitness rebuilding. The fitter I am, the easier it will be to deal with all the medications and treatments.

### Cancer itself

It really has been a time of processing the whole experience. I know it takes time. I have noticed that I have been keeping myself quite busy going to appointments e.g. art therapy, Pink Pilates and cancer support appointments. I think I will cut down on these as firstly, I just get tired. But secondly, I think being busy is a distraction mechanism for actually being still and processing everything

I've been through this year. It is easier to whiz around to appointments in the name of being healthy. It is far harder to come to peace with cancer and sit with it.

I went a bit over the top with the cancer rehabilitation. One book recommended charts of monthly and six monthly rehabilitation goals across eight headings. Honestly, I got tired just doing the chart. There is something to be said for just time, fresh air, exercise and eating well. A lot can heal with that and a positive mind-set. I have put the charts to one side.

## Herceptin and Hormones

DECEMBER 19, 2011



Hormones are everywhere. I suspect that I'm having a not-great reaction to Exemestane, the hormone therapy I am taking. Sometimes, I am physically shaking, nervy and anxious (a feeling of low blood sugar when I don't have low blood sugar) plus little things seem very big. It is not pleasant. My oncologist told me to try taking the medication in the evening instead of the morning; then stop it if I didn't feel better. Well, I'm not feeling better yet. But perhaps Christmas isn't helping with a turbo pace around me.

My last Herceptin treatment went really well on Thursday. My sister-in-law picked me up at 11am and I had just taken 1 anti-anxiety pill plus 1 anti-nausea pill. We went to a favourite café opposite the hospital and had zucchini and carrot fritters (very nice). Then in to the hospital at 1pm.

It was good as there weren't many people in the ward. The nurse got the needle/cannula in easily and it didn't hurt. She took a blood test and then started with a bit of saline, then the Herceptin.

The nurse was lovely and we had a good chat about Wales. That was fun as I had just been in Cardiff in April so we were talking about the great shopping and that I saw the X-Factor concert while I was there.

I had asked to see the oncologist; she came over and chatted to me in the ward. I have been experiencing this new kind of low blood sugar thing (sometimes



after exercise) and numb hands. She said to take my hormone pill in the evening instead of the morning and then stop it if this continues.

Then as the Herceptin finished, the nurse gave me a little homemade Christmas cake which was nice. I also talked to a nurse about the possibility of having a private room (as going into the hospital makes me feel a bit sick e.g. hospital smells, looking at other people having treatment etc.). She said that they do have two rooms like that and she will write that on my file so I can have one room unless it's busy. I'm really happy about that as I didn't want to be a pushy patient.

It all went well and I felt fine... a little dreamy from the drugs but fine. I got home just before 5pm.

On Friday, I felt tired and had a dull headache but was okay. I still feel that I am only able to do one thing a day e.g. one outing or activity. If I do more than one thing, I need to recover afterwards, not just rest.

My work has told me that there is no assured part time role for me. That has made me a little anxious but I guess I can't tell them an exact day that I will be feeling better. It is still hard to know when I will feel 100% again but my doctor has advised me to start part time work gradually and not to work full time for at least a year. For example, start with four hours per week and then increase to eight hours when I am used to that.

I have an appointment with the breast surgeon tomorrow so another hospital day (not the whole day but it takes over two hours driving to get to the hospital and back).

I am struggling a bit with my own expectations that I should start work soon and fighting against the reality that I am not feeling healthy enough to do that.

What has been going well:

- Exercise routine – apart from Christmas activities, I have been maintaining a good exercise schedule with mostly biking.
- Herceptin treatment – this one went a lot better plus I have been told that I may have a private room next time.
- Lots of rest and cancelling appointments if I feel tired.
- Talking to supportive family and friends. Having good support at medical appointments.
- Talking to my doctor, oncology nurse and oncologist regularly. I am lucky that I can email my oncologist.

## Herceptin, Hormones and Christmas

DECEMBER 26, 2011



Christmas on the beach

I don't want to be negative but I haven't had a very easy week. I think coming up to Christmas with a lot of social events that I'm not used to, plus icky side effects from the hormone therapy. It has been one of my worst weeks yet.

The chemo side effects still continue:

- My hair is still falling out at exactly the same amount. I am starting to see patches within my hair. The oncologist was right though; no one else would notice it. My scalp is a little sensitive but not too bad.
- Bleeding noses; I seem to be getting these every day off and on. Sometimes just for a minute and other times, for up to an hour.
- Fatigue; I am able to do one outing a day and if I have more than that, I am over-tired and feel unwell.
- I had a whole day migraine on Tuesday. Not fun.
- I'm still not sleeping.

But overall, the side effects are disappearing.

### Hormone therapy

I have had a challenging time with the Exemestane (hormone therapy). I have stopped taking Exemestane after discussing the side effects with my oncologist and oncology nurse.

These drugs are important as they reduce local breast cancer recurrence by around a third. But I felt terrible. I started taking Exemestane around 1 December. Within a few days, I started feeling anxiety, on edge and shaking. I had headaches, numb hands and feet plus felt faint every now and then. It wasn't good.

On 19 December, I stopped taking the medication and the shaking feeling disappeared within a day or so. Two days later, I had a full day migraine plus panic or anxiety attacks. It has been a busy week and I am a bit over-stimulated especially with the mayhem of Christmas but it has been downright yucky. Also, during Christmas, it is hard to talk to health professionals as they are on holiday.

I am looking forward to all of that stabilising and the new year.

### I met with my breast surgeon this week:

- The breast is healing nicely and she said that scars will soften to a white line within a year or so. She recommends continuing with Bio-oil.
- I asked her what was the best way to care for the new belly button as no one had really told me: I dry it out after showering with a Q-tip/cotton bud and she confirmed that this was right. It is quite a different type of belly button and does take time to learn to live with it.
- We don't know the date for my third surgery but I said for now, that was okay as I was hospital-ed out.
- I asked her about genetic testing for breast cancer. She said that I wasn't a candidate as my breast cancer was triple positive (progesterone, estrogen and Her2 positive) whereas the genetic type of breast cancer is triple negative (progesterone, estrogen and Her2 negative).

- I discussed the hormone therapy with her. She said that my estrogen therapy hadn't worked in the past as the HER2 positive-ness was stronger than the estrogen positive-ness (HER2 trumps estrogen). So in a way, it didn't help that much to take the estrogen therapy (my words). I wonder how important it is to take hormone therapy then? I will ask the oncologist when I see her in January.
- My surgeon told me that it should be my goal to rejoin the world as she is planning on me doing well.
- She told me that there is nothing magical in terms of supplements, vitamins etc to prevent breast cancer. But sometimes people feel that they are in control by taking these.

#### What has helped me:

- Talking to the oncologist and oncology nurse.
- Exercise every day, walking on the beach or biking and getting into nature each day.
- Writing every day about things that have gone well and not gone well.
- Talking to understanding people.
- Resting.
- Celebrating end of chemo and my birthday.
- Planning fun things in the future with friends

# 2012 Chemo Diary

January, 2 months post-chemo

**2 January 2012**

JANUARY 2, 2012



## Happy New Year

Well I am starting to feel better and better. I think the chemo is out of my system but there are side effects lingering; my hair is continuing to fall out and my scalp, still tender. My nose is bleeding off and on and I have headaches quite often too.

Christmas tired me right out so I have spent days resting but have been able to bike or walk most days. I also still get tired and need to rest for probably half the day. I don't seem to be able to tolerate much additional stress. I can usually do a short outing plus exercise each day.

Sleep is probably my biggest bugbear (that I can't sleep well).

I think the Herceptin is continuing to cause nerve damage in my fingers and feet. I have my 7th Herceptin cycle this week.

## Hormone therapy

I finally got those horrible side effects out of my system about two days ago. That hormone therapy just didn't suit my system and I felt awful. Going off it was worse than being on it. But hey, I have survived. I now need to decide whether I go on another one.

I am starting to look at working part time around the Herceptin treatments. I feel resilient but not up to the pressure of business as usual.

I am looking forward to rebuilding my health in 2012!

7 January 2012

JANUARY 7, 2012



Herceptin #7 of #17

I have had a milestone. I think my hair has stopped falling out.

I had Herceptin on Thursday. The hospital was a bit full as staff had been on holiday on Monday and Tuesday. So 30 minutes of Herceptin took 1.5 hours. But it was not their fault and it went okay. A friend came with me and that made it an okay day.

Afterwards, I felt tired and like I had a cold. Just run down and a bit weak with bleeding noses and slightly numb hands and feet.

But I am overall feeling a lot better, especially with that hormone therapy out of my system. I still can't sleep well but I am hopeful for an improvement soon.



march, 4 months post-chemo

## Half Way Through

MARCH 12, 2012

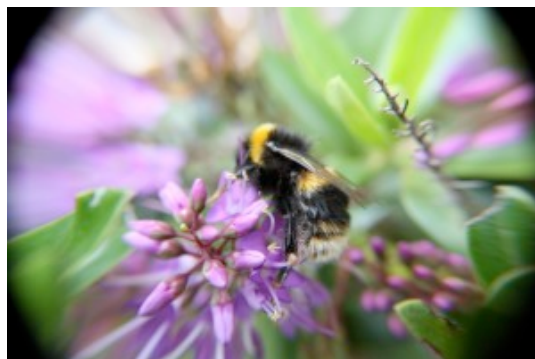


Photo by Heather Carver

I've reached the half way mark for Herceptin. As of last week, I completed Herceptin Number 10 out of 17 Herceptin treatments. Treatment goes for a year and is every three weeks. When I reached the half way mark in February, it just seemed daunting to have another six months to go. But now that it's March, it's only five months to go. Breast cancer treatment can take a long time but it is an investment in my future.

### Highlights in the last few months:

- **Hair not falling out.** My hair has completely stopped shedding and my scalp is no longer sore.
- **Sleeping properly.** Somewhere around mid-January, I started sleeping properly without medication. In fact, I started sleeping 10-12 hours a day. It is a huge relief I must say.
- **Slightly improved skin.** My skin no longer looks like chicken pox on my face but there is definitely still a problem with acne breakouts on my face and neck. On talking to my Doctor and Breast Surgeon, my body is

still processing all the surgeries, chemotherapy and Herceptin. They recommend normal acne medication.

- **Getting back in to normal life.** I have moved out from living with my parents and am flatting on my own. It's nice to have some more independence back and see more friends. Also time to process everything that happened in the last year.

#### Still challenging:

- **Nose bleeds** are still around; not as bad but just here and there, caused by the Herceptin and chemo damaging membranes. Tip: My breast surgeon said to use Vaseline; dab a bit up each nostril to protect the nose.
- **Headaches.** These are my main issue at the moment. Sometimes up to four days out of seven. And unfortunately, do not respond to any pain killers that I have tried. I think it is a combination of just a lot of change and stress, with the medications.
- **Slow pace still.** I still have limited energy reserves. I can do one or two outings or appointments a day if they are not too full on. But if I cross the line, I get very tired. I still don't schedule very much but at least, I can go out and do stuff pretty much as normal.

Other than that, I am doing well. I am back into many of the normal routines and really enjoying putting time into the Breast Cancer Nirvana website.

#### Hormone therapy

On discussion with my oncologist and breast surgeon, I decided not to continue with hormone therapy at this stage. I had already been taking hormone therapy for around 4 to 4.5 years and then had awful side effects when I tried the last one. Apparently, the estrogenic level of the breast cancer tumour was

approximately 20% which is not that high. The HER2 positive level was higher and for me, the most important thing is for me to complete the Herceptin treatment year (a total of two years in the last five years). N.B. every type of cancer is different and I am not advocating this move for anyone else; it is specific to my diagnosis.

What has helped me in the last few months:

- Support from family, friends and various complementary therapists (EFT, art therapy and Pink Pilates mainly)
- Fun times and chats with friends
- Time to rest, sleep and recover
- Exercise daily (walking and cycling mainly) and getting in to nature
- Writing down my experiences
- Having a project (in my case, the website)
- A fantastic medical team (oncologist, breast surgeon, plastic surgeon, doctor, natural health therapists and excellent nurses).

## tip

- Take good friends and family to appointments with you. The appointments are just easier that way.
- Have headphones and a book with you (so you can stay relaxed and not too involved with other things taking place in the chemo ward).
- If blood tests are difficult (i.e. like me, veins are hard to find), have the blood test done on the chemo day once they put in the cannula (get to your appointment much earlier for that and let the nurses know in advance).
- Take as much time as you need or is practical to recover and get yourself back from cancer and treatments.
- Accept support from others, and especially accept laughter and fun outings.
- Create a ball of positivity around you while you are ill, going through treatments and recovering. It is important to stay as positive as possible and reduce all stressors around you so you can heal 'you'.
- Stop people when they start to tell you negative or depressing stories about cancer. There are many positive survival stories out there (the other stories are important but this is not the time to hear all the stories that don't have happy endings).
- Cancer retreats have been a wonderful focus for me.

May, 6 months post-chemo

## Herceptin #13 out of 17 Cycles

MAY 13, 2012

I just had my thirteenth Herceptin cycle. I only have four more to go... and that will be one year of Herceptin. It went well. I get quite tired from the Herceptin and feel like I've got a hangover for five days afterwards. My main issues are headaches and migraines. On a good week, I have 1-2 mild headaches and on a bad week, one migraine and a few headaches. The trick with these is that they don't respond to painkillers. I think they are a special type of Herceptin headache. They are enough to stop me doing quite a few things.

My oncologist requested a CT scan of my head to rule out any other issues. Two weeks ago, I had the scan and it was not much fun. After three attempts to find a vein and 30 minutes or so digging around, a vein was found. Then down for the scan and a contrast dye was injected into the cannula as I went in for the scan. It made me feel nauseous for the rest of the evening. But yes, the CT scan was clear so 'big' issues were ruled out, thank goodness.

My tips for CT scans are: to get the line/cannula inserted by the oncology nurses who do this all day every day. Then while having the scans, to close your eyes, meditate, visualise yourself on a sandy beach or your favourite place; just don't think about the scan or going in to that tube as it can be a bit claustrophobia inducing.

What is working for me is that I have been having acupuncture. In acupuncture terms, headaches are easy to treat so I hope to see good results.

### Only four to go

As I'm nearing the end of my treatment, the oncology nurse started to prepare me for this milestone. I was given an 'After Cancer Pack' full of resources

on life after cancer and the transition between treatment and normal life. I've been through the transition before. It is kind of eerie... on one hand, yippee no more injections, medications and down to annual check ups. On the other hand, there is suddenly time to process everything that has gone on in the last year or so where I have been surrounded in medical cotton wool. After I finish Herceptin, I no longer have the support of a team of medical professionals. It can feel lonely, isolated and fears of recurrence abound. This is the time when many cancer survivors need more support – counselling, post-cancer programmes – and often, depression arises.

I am starting to plan the celebrations and also, recognise that a different life will begin. A life when it's time to make plans without fear of cancer while simultaneous not having full health – until full health comes back in its own time.

Cancer has been the main thread in my last 5.5 years. In 5.5 years, I have had breast cancer twice, had nearly two years of Herceptin, nine months of chemo, six weeks of radiation and had five surgeries included a full mastectomy and breast reconstruction from my tummy. It is a lot for a body to process and takes time to recover! One medical professional I talked to recently said it would take five to ten years to get myself completely back to full health, not in a negative way but in a 'let's get real' way.

The rest of the time has been spent working, getting my health and fitness back and getting out there in the world. I have travelled for work and pleasure to Scotland, Wales three times, Portugal, England, Ireland, Singapore, Brazil, Argentina, Viet Nam, Australia and around New Zealand visiting friends and family. Travel is my passion and helped me get my mojo back after cancer last time. I have also worked hard and done lots of social stuff and met lots of new friends including on a three week holiday to Brazil and Argentina.

I am looking forward to the next phase of my life – with adventures, a new career, the website, writing, travel, all sorts of things. I can't wait but I'm also a bit cautious about not committing to too many things while I'm not 100%. While I

can't wait for the future, I also need to focus on the now. Not count my chickens before they hatch... get to the gym, watch my weight, go to my medical appointments and live as well as I can.



But in the meantime, I wanted to do something outside the square so had some navy blue streaks put in my hair and I'm loving it.

June, 7 months post-chemo

## Herceptin 14 out of 17

JUNE 10, 2012



Last week, I had my 14th Herceptin cycle out of 17. I only have three more to go with my last one on 2 August. I am rapidly approaching the end of the cancer triathlon – surgery, chemo and Herceptin.

I am doing well overall.

### The main issues of late are:

- My immune system is still compromised. Until quite recently, I had bug after bug since March. It was tedious to say the least.
- Headaches and migraines. I still seem to be getting a lot. A migraine about once every 10 days and headaches up to four days per week. Last week, I had two migraines, Wednesday and Thursday! It is a terrible feeling to wake up with a migraine. Let alone, two days in a row. My doctor has prescribed a medication with a side effect of reducing headaches so I am now taking that in earnest. I am also having acupuncture once a week and seeing a chiropractor regularly to help with the headaches too. The main impact of the migraines/headaches is that it's quite hard to get things done and I feel behind in most things.



- Other than that, after Herceptin, I usually just get a bit swollen and tired (sleeping up to 12 hours for a few nights after Herceptin).

In terms of recovery, I still aim to do exercise daily and eat as well as I can.

I had a MUGA heart scan last week. So far so good in that Herceptin has not impaired my heart function so far. It is monitored each three months.

I still have problems with fatigue but mainly in scheduling activities. Even though I know that I can cope with one or two activities a day, sometimes I schedule more activities and push myself a bit hard. Also, I decided to organise a website launch but kind of forget how much work was involved. I do about an hour of day of work on the launch each day and if I do more than that, it seems to wear me out too much. I am lucky to have a group of volunteers working on all aspects of the launch for me. And I am sure that the event will go swimmingly. But I'm not quite able to handle things that I might have handled quite easily in the past. It is confronting to realise that I can't do things that I used to do so well.

A friend of mine in Australia was diagnosed with breast cancer recently. She had surgery last week and her attitude and strength is amazing. I am constantly amazed about how strong and resilient people are.

#### What is going well:

- I am feeling good about life post treatment. I'm not sure exactly what I'll be doing but I am feeling positive.
- I am realising that I have things to offer others going through breast cancer. The website has had a life of its own and I'm enjoying doing it.
- The acupuncture and chiropractor appointments are helping.
- Having a great group of friends and family helping with my website launch.
- I have an article featuring in the Cancer Society July newsletter.
- My skin is really good and my body feels healthy.

- I have an excellent team of medical specialists around me.
- No pressure on me to return to work straight away but starting to think about a part time job post-Herceptin.

July, 8 months post-chemo

## Two Cycles to Go

JULY 3, 2012

The last two Herceptin cycles were quite different. The second to last one made me feel tired, a little nauseous and I had quite a few headaches. With the most recent one, I felt really good. It's interesting how each cycle seems to have its own personality.

I have still struggled with headaches and migraines. I started taking a headache prevention medication and definitely they reduced but not completely. Last week, I had so much to do and lots on my mind and I ended up having two migraines, two mornings in a row. So I haven't quite got the answer to migraines yet. But going to acupuncture helps as does the chiropractor. The main thing seems to be keeping my stress levels way down and perhaps giving up chocolate.

### Finishing treatment soon

So here I am in early July and I only have two Herceptin cycles to go. I can not wait to stop going into the chemo day ward each 21 days and putting pressure on these fragile veins on the back of my left hand. However, it also feels odd. I have been in the hospital system since April 2011 having surgeries and chemo and whatever scan. It feels precarious to leave the safety of the hospital. I guess I have been institutionalised to a degree.

I know what to expect from having breast cancer last time: for a few months after treatment ends, there is an anxiety in existing without doctors constantly doing check-ups. It feels like my life and body can't be trusted and that I need to be monitored more. But after a few months, the feeling starts to subside and turns into anxiety around the time of follow up appointments e.g. a

mammogram, or the five years of follow up appointments with my breast surgeon. Each time I return to the offices where I was diagnosed, I feel a bit upset.

### Fear of recurrence

All the feelings of trauma or nausea are triggered each time I go back to the hospital and meet my surgeon. Even when she will say “everything is fine”, I feel suspicious. In my mind, there is a conversation that goes something like this “well, I felt fine before but I wasn’t fine – so surely now, I have to be extra vigilant about looking for cancer in my body”. Every ache or pain, lump or bump triggers an anxiety or tears. Is this cancer again?

Well no, it’s actually an illusion, my mind is tricking me. At this point, I am cancer free and from my research, any lump in my body that is suspicious will be found by a mammogram or my specialist at about the same time as I would find it just living normal life (as I have regular appointments with a breast surgeon). So I can relax and forget about cancer and let the specialists take care of that.

It does feel surreal as I am getting to the point where I can kind of forget about cancer. It takes longer than that mentally though. And there is a tiny anxiety that after four and a half years after the first breast cancer, I had completely forgotten about cancer. And then, there it was again. But once again, I must go out in to life and forget about any fear of recurrence. My best medicine is to live without any fear, have fun, live a balanced life, have check ups...just get on with it.

### The new life plan

Time will heal everything and fingers crossed, I will not be going through this all again. Maybe I can start to plan the next stages of my life. I will finish Herceptin, let Herceptin leave my body over a few months...and then, start my new life. It is exciting but it feels quite big. Another big milestone is just around the corner.

I feel that I have changed a lot with this breast cancer and all the treatment. It has made me realise that life is short-lived, and not to concern myself with doing things for stability, security or money. It is time to live as if I have no fear of those things. To stand up and be me, and just do what I want to do and what makes me happy.

#### What helps with the fear of recurrence?

- Getting the facts from your specialist. There is no need to constantly monitor yourself or live in fear.
- Counselling or other types of emotional therapies. You have been through a trauma and it is time to heal all these difficult experiences.
- Support – seek out support from a friend or a group that understands.
- Time is the great healer. Take time to recover from breast cancer and gradually fears will diminish.
- Plan an end of treatment celebration or holiday.
- Write about your experiences and get the feelings out of your system.
- Read cancer support resources on finishing treatment and talk to a nurse.
- Don't ignore the fear but do something to reduce the fear.

#### What has helped me at this milestone point?

- Friends and family.
- Fun – doing enjoyable things.
- Writing down my feelings.
- Planning an end-of-treatment holiday to the South Island with three friends.
- Talking to supportive people/networks.
- Art therapy.
- Not putting pressure on myself to go back to work until I'm feeling a lot better.

- Leaving major life plans until now – not trying to work it all out well in advance of the end of treatment date.
- My website has been great therapy and a positive focus.

August, 9 months post-chemo

## My Final Herceptin

AUGUST 2, 2012

Today, I had my final Herceptin treatment filmed for New Zealand television show Tagata Pasifika. I wanted to show what receiving cancer treatment was like to reduce fears of cancer.

It's been a strange day. I woke up early with a migraine, then got stuck in a traffic jam for 45 minutes turning up to my appointment late. I met my friend and then at the hospital, we met with Sandra Kailahi from [Tagata Pasifika](#). Two other friends also arrived so there was a big support group. My mum then turned up with home baked scones to thank the nurses.

The appointment with my oncologist went really well and she was then interviewed by Sandra. My oncologist told me that I'd be having three monthly check-ups for a while and she wished me all the best with my milestone today saying that I was cancer free. Sandra then interviewed me and my friends.

Thanks to everyone for their support, time and energy today to make filming a success. It is not easy to talk about breast cancer for TV but everyone looked and sounded great. I'm not sure how my interview went as I was a bit tired but I did my best.

My mum, Gill and I went out to celebrate at my favourite restaurant. Yay, it's all over.

Here are some photos from today:



Me and my brilliant nurse



Being interviewed by Sandra from Tagata Pasifika



## End of an era but not quite

AUGUST 18, 2012

It's two weeks after my last Herceptin and I wanted to be writing to tell you that everything is different and better. But unfortunately it ain't. What has been challenging is an increase in headaches and migraines. In the last week, I had headaches and migraines for five of seven days. Plus a feeling of displacement – out of the hospital system, not sure what the future holds mixed up with a fear of a recurrence. I feel a bit flat. However, I am working on all of that stuff and it is very normal when finishing breast cancer treatment.

I do have good days though and I had a brilliant weekend away. My friends and I went to Hanmer Springs for the weekend. It was a real celebration and I enjoyed every minute of it. Especially the [thermal hot pools](#) and [restaurants](#).

I feel a bit behind with things. Lots of tasks that were meant to be done but were shelved when I had a migraine. I have achieved some of it but not much really. Then, when I have a non-headache day, I start getting into almost a panic attack trying to catch up with lists of tasks to try and catch up; there seems so much to do but it's just a spiral in my head.

There are also things to organise. I will be moving house shortly but haven't found the house yet. And also planning a holiday to celebrate the year. So all of a sudden, I am in organisation mode.

### What is going well:

- **An amazing weekend** in Hanmer Springs with hot pools, restaurants and good friends.
- **An overall plan** for the next few months – recovery, moving house, a holiday and doing some writing.
- My **energy levels** are getting better.
- **Acupuncture** for headaches, migraines and overall wellbeing.
- **Chiropractor** is helping too.

- **Mediation and mindfulness CD** by Stephen Archer.
- **Art therapy.**
- **EFT** for looking for the cause of the headaches.
- **Good friends and family.**
- **Cycling and walking** most days.
- **Being able to do nothing** on days when I don't feel well.

What is challenging:

- **Fear of recurrence.** It's hard to see that my future will be smooth sailing but I am working on changing those beliefs as they don't serve me and create anxiety.
- **Headaches and migraines** – it's hard to do things when there's a headache, especially the ones that don't respond to any medication.
- **Finishing treatment but feeling flat.** It would be nice to feel happy that I've finished treatment but it doesn't feel like that. However, time will be the great healer.

## Being Declared Cancer Free

AUGUST 23, 2012



Three weeks ago today I had my last Herceptin treatment. For the last year, every third Thursday was the day I went into the chemo ward. Here I am – on this Thursday – feeling strange. It has been my norm to be in hospital and here I am at home contemplating being cancer free.

My oncologist told me that I am cancer-free. These are huge words. In April last year when I was feeling very healthy, I was told that I had breast cancer and here I am in August 2012, feeling a bit weary, and I am cancer free. Cancer seems so arbitrary and like a trick sometimes, especially as much of it is invisible.

Don't get me wrong. I welcome being told that I am cancer free. I prefer my life to be this way. But my mind is a bit institutionalised, used to planning things around hospital appointments.

### Optimism

After three weeks of feeling a bit indifferent about being cancer free, I am starting to feel quite optimistic and interested in life to come.

But focusing on right here, right now, I'm starting a few new endeavours. The first, is working with a reputable herbalist to compliment other therapies. I've always followed conventional plus complimentary therapies (but some complimentary therapies e.g. some herbs should not be mixed with chemo

medications). So tomorrow, I have my first appointment and the focus will be on headaches/migraines and side effects of the cancer medications.

I am still experiencing lots of headaches and migraines and they are very boring. I tried another headache prevention medication but I felt like a zombie so no thanks. It's best to stick to a bit of Voltarin and an anti-nausea medication during the migraine. But when I don't have a headache, I am feeling quite good.

I have been doing EFT to get to the cause of the migraines and even though, half of the cause is simply Herceptin, I think there was a bit of anxiety about the future underneath. So I have worked with a skilled EFT practitioner to get to the bottom of things.

I am still doing acupuncture weekly and that is going really well.

I have planned a holiday and am really looking forward to this. When I return, I will move house and then, I'll be ready to start looking for part time work.

A good friend gave me the best advice when I was diagnosed with breast cancer. She said "treat breast cancer as a job, then recovery as a job. Then have a holiday before starting work again. Time off work for cancer treatment is not a holiday". I feel happy with taking this approach, and it will be great to have a proper holiday and end the year on a high note before getting back into the productive economy.

#### What has been helping me:

- **Friends and family**
- **Acupuncture** and talking to a Herbalist
- **EFT**
- **Planning a holiday**
- **Having time off** to recover from treatments
- **Meditation and mindfulness**
- **Exercise** every day

# September, 10 months on from chemo

## I've Turned a Corner

SEPTEMBER 2, 2012

### No migraines

It's four weeks on from my last Herceptin and I have turned a corner. Thank goodness. Since June, I have had two migraines a week plus headaches totalling up to five days out of seven. It has been a pain, I tell you. But as of today, I have not had a migraine for thirteen whole days.

I have gained three kilos since June and I think it's just from being out of action with all the headaches and migraines. The most annoying part about them is the inability to get much done in a day or a week. On a migraine day, I would just rest and recover from that and sometimes, I had migraines two days in a row. So then, when I felt better, I tried to catch up on everything that needed to be done. (By the way, it is impossible to catch up on a week's worth of activities in two days. Logically, I knew that but I felt so behind with everything.) I'm now gradually catching up with some things.

So as the Herceptin is coming out of my system gradually, I am feeling better and the side effects reducing. It takes around three months for the Herceptin to exit completely. Also, I've had four surgeries in just over a year and three months of CMF chemo and lots of other medications. So finally, I can start to recover properly. My skin isn't very good though. I'm sure the weight will start to come off gradually over the next few months.

### Gradual re-entry to life

Mentally, I am feeling different too. I would say more optimistic about the future and feeling happier in myself. Time is a great healer. I'm noticing that I can

concentrate better on lots of things including reading, writing, crosswords etc. I didn't realise how bad my concentration had got.

So it's a case of gradually catching up with life and moving forward. Not trying to do everything at once which is easier said than done. I seem to have a driver inside me which gives me huge sets of tasks that don't get done. But hey, apart from a cold at the moment, I am getting there slowly but surely.

It is strangely freeing to start to feel more well; freeing but also, slightly overwhelming. I can't remember what I used to do with so much free time. Oh yes, work and see friends. I haven't had much energy or felt physically good since April last year. I am having to re-learn normal behaviour now that I have more energy. I have even started doing yoga again, about 30 minutes each day, plus doing a cycle or walk.

I guess it's time to set some new goals, get back to some part time work, get out the bucket list and start gradually making things happen.

### Herbs

I had a Skype consultation with a naturopath and herbalist. I am going to take some herbs for the next three to four months to help clean up any medications affecting my liver. Plus taking probiotics to rebuild my immune system after quite a few antibiotics. I am happy about the recovery and rebuilding path ahead.

### What else?

In the next month or two, I'm moving house as I made a promise to myself that I wanted to improve my lifestyle post-cancer. Having cancer once is a blip. But having it twice in five years is slightly more than a blip. I want to improve my health overall (by changing the things that I can control e.g. stress levels and the resulting stress hormones). So I've decided to move out to the beach and have a more relaxed lifestyle.

It will be quite a transition moving away from the city life but I am not attracted to the rat race lifestyle any more. It will be interesting to see what kind of work I can do from there. That will be the next step.

### Holiday

I have also planned a holiday to France. The main destination is the healing place of Lourdes. it'll be great to bring back some healing water and just experience a sacred healing city. Any bit of healing helps and I just felt I wanted to end the year on a high note after so many treatments. Life is short lived and it's great to do things this year rather than wait five years.

### What is working for me:

- **Acupuncture, herbalist, art therapy and chiropractor** appointments
- **Friends and family**
- **Daily exercise** – yoga, walking on the beach and cycling
- **Planning a holiday**
- **Planning a gradual re-entry to work** once I'm feeling a lot better
- **Breast Cancer Nirvana** and feedback from readers!
- **Meditation**
- **EFT**
- **Cancer support programmes**

Thanks to everyone for your support – and putting up with boring, endless stories of headaches and migraines.

17 September 2012

SEPTEMBER 16, 2012

### Seven weeks on

It's seven weeks since I finished Herceptin and I am feeling a bit better each week. It is almost a month since I had a migraine. I can't tell you how life changing that is. I now can actually do some things consistently. I still have a couple of days of headaches a week and wake most days with a kind of seedy, nauseous feeling. But that is usually gone by the afternoon. I usually need to start the day very slowly. I still have a bit of fatigue but am focusing on building up my fitness. Also my concentration is improving.

### Cancer Rehabilitation

With acupuncture, we are working on bringing up my digestion and liver function instead of constantly focusing on headaches and migraines. And my acupuncturist has taught me a few qi gong exercises to build up my energy. I am finding those really helpful. Most days, I go for a bike ride or walk.

I am also taking herbs and supplements to rebuild my body after all these treatments. I am taking a pro-biotic to rebuild the good flora in the intestine, herbs to help move residue of all the medications I've taken for the last year or so and a good anti-oxidant. I am just getting used to the new system of taking them as the herbs are three times a day and need to be refrigerated.

### Moving on

At the end of the year, I will start looking for part time work. I am starting to feel that I can contribute in a small way and consistently (without having to take sick leave constantly for migraines etc). As I feel better, I want something for my brain to do plus more social interaction. The challenge is to find work that doesn't use up all my new found energy and doesn't put too much pressure on me and my health. So starting gently in a supportive environment.



There are lots of decisions to make about where to work and live etc but I will leave the decisions until the time I need to make them. That is new for me as I used to plan things way in advance.

My overall goal is to live a healthier lifestyle and really enjoy everything I do. It is a new way of thinking for me. It requires knowing who I am and what suits me. And prioritising a healthy lifestyle over a stressful job, working too many hours etc. It feels pretty radical to move out from the rat race.

It is starting to sink in that I am cancer free and that I can make plans for the future. I am feeling a bit more positive about life but still feel the effects of so much cancer treatment over the last few years.

What is not going well:

- When I have **headaches**, they usually do not respond to medication. So having pain for a whole day starts to get me down. A doctor suggested that I don't take any headache medications at all as there is a toxic build up. So it can be a bit challenging at times.
- **Lots of aches and pains** too small to mention; all the accumulation of side effects from all the surgeries, chemo and medications.



What is going well/helping me:

- **Art therapy, acupuncture and Qi Gong**
- **Eating** really well
- **Friends and family**
- **Writing** for Breast Cancer Nirvana
- **Doing exercise** daily – getting out in to nature e.g. walking, cycling etc.
- **Listening to my body** about what I am able to do
- **Planning a post-cancer holiday.** I will end the year on a high note!
- **Taking herbs and supplements** to support my recovery
- **No migraines** for nearly a month!
- I've now had a few **celebrations** of finishing cancer treatment. That's been great.

## On my way to Paris

SEPTEMBER 22, 2012



After I finished my last Herceptin treatment, I had this brain wave...why don't I end the year on a high note by doing a holiday? It has a few purposes – going to Lourdes, a healing sacred place plus ending a very challenging year with something really positive. Luckily, there were some special sale prices with flights. So today, I am on my way to Paris. I will keep you posted on my trip.

## Living some dreams

SEPTEMBER 24, 2012

Here I am in Paris. I arrived last night and went straight to my hotel. The flights were taxing to say the least. But I am here now and pondering why I wanted to come so much.

I just went for a walk around and found a cafe called Villa da Andrea. I thought that was a sign so I went there for lunch.

While there, it struck me what this trip is about. I am not in a hospital ward, I do not have a vein in my hand and I do not have cancer anymore. I am in Paris and I am okay. And there will be other good things in my future. This trip is about getting back out in to life and realising that my life is starting again. There can and will be more good things!

## Sunday in France

SEPTEMBER 30, 2012

Bonjour! The weather is both sunny and rainy in France. I still have not learned my way around a French keyboard but I am getting there. France is very beautiful and I am lucky to be here. Today we head to Lourdes. It will be interesting to see the place and collect some healing water.

I have made some new friends and one of the benefits of travel is seeing my world differently as well as a bigger world. I have some ideas for different things I want to do on my return to New Zealand. However for now, it feels like cancer and cancer treatments were a long time ago which is a great feeling. Apart from jet lag, I am feeling very well here, sometimes walking three hours a day.

october, 11 months on

## Going to Lourdes

OCTOBER 2, 2012

Two days ago, I went to Lourdes. Lourdes is one of those spiritual places where people go for healing. It is not peak holiday season and we did not have big waiting times. There was a line to go to a grotto where healing water from a spring came out of rocks. Then there were a number of taps so that people could drink or collect the spring water in bottles. To the side, there was a church with beautiful murals. It felt like a peaceful place. I drank some water and filled a few small bottles.

I can understand why people go to Lourdes. Life can be so uncertain and sometimes, treatments do not work as planned. We can compliment conventional treatments with things that are perhaps outside the box. Whatever way you look at it, it cannot hurt. Miracles have taken place at Lourdes and I felt peaceful there. Peace is good and especially good for my health. Now I am in Bordeaux...it is so green with grapes everywhere.

## The Light is back on

OCTOBER 11, 2012

I wanted to come on holiday to France for a few reasons. Partly, it was about ending the year on a high note. I did not want 2012 to be defined by breast cancer only. Instead I will have France stories to tell. But something more has happened on holiday. I feel I have got myself back from breast cancer.

I have had no migraines and have been walking up to six hours a day. Somehow the stamina has come back. It is a combination of the amazing art and history, meeting new people and getting outside my comfort zone. Here I am just a normal person having lots of laughs, conversations and new experiences. I think also visiting so many sacred sites including churches, Lourdes and Normandy have also helped in the healing process.

I am feeling good, despite bronchitis, and looking forward to my final week in Paris and coming home with fresh ideas and inspirations.

## Two steps forward, one back

OCTOBER 15, 2012

Healing never follows a linear path. Despite feeling good mentally, my body has been unwell for ten days – chest infection, bronchitis, throat infection and not able to breathe very well. Even though I am on the recovery path and in amazing Paris, I do not feel very well. I fly home on Wednesday and I am mentally preparing myself to do the two 12-14 hour flights while not feeling 100 per cent.

I am really looking forward to getting home, seeing my friends and family and getting on with my normal life. I have lots of plans and am so grateful to have had this experience to help me get out of feeling that my life was starting to be defined by breast cancer. Instead, I have had lots of laughs, inspiration, great food and come away with new friends in France, Australia and the United States.

I learned how to use the Paris metro, saw so many Van Gogh, Renoir and Monet paintings and have marvelled repeatedly about French history and culture. It has been a great trip. But now, if I could just get well and enjoy my final two days.



## My Three Month Check-up

OCTOBER 29, 2012

On 25 October, I had my (nearly) three month check up with my oncologist. It did feel weird going into the Blood and Cancer Centre. Already, it felt like this was the past and I almost couldn't quite remember how to get there. In the waiting room, I distracted myself with reading materials and had to wait for about half an hour before I was seen.

A nurse called my name and took me over to be weighed. I had lost four kg since I was there last time (great). In the consulting room, I went over my questions and queries. But really, I didn't have much to ask.

When my oncologist arrived, I told her that my migraines and headaches had reduced significantly from about Week 4 after the last Herceptin. She thought that was interesting and great, and congratulated me on my weight loss. I have 3kg to go to get back to pre-breast cancer weight.

My oncologist didn't examine me as I don't have any issues to report. She told me that I didn't need to see her again unless I needed to. My next follow up appointment is with my breast surgeon in March 2013 and I have a mammogram scheduled for January.

So the appointment was delightfully uneventful. And I guess I am not on three month follow up appointments anymore. It will be five months until I see my breast surgeon. However, I have a follow up with my plastic surgeon in ten days. It will be good to see her and double -check that everything is fine. Onwards and upwards with life.

November, 11 months post- chemo

## Transitions

NOVEMBER 4, 2012



Well I've been back from France for just over two weeks. It has been an interesting re-entry with a few challenges and a few triumphs. Getting over the chest infection plus jet lag was a bit of a challenge. Last weekend, I stopped sleeping like a vampire, highly alert in the middle of the night. It has taken a while to normalise so to speak.

I have caught up with some friends and family now. It's been great to see everyone but with a couple of sad occasions (with the passing of two friends' mothers). It was great to be here and be able to support my friends in my small way.

Post-holiday syndrome has hit a little. France was such a highlight and it has been tricky coming down from that to normal life in New Zealand. I am starting to think about work and finding a new place to live and realise that my goal setting and self-confidence needs a bit of attention. I got really good at handling breast cancer but handling normal life events takes a different set of skills that are either rusty or hiding.

I have been trying to re-discover the routine that I had before I went away. Exercise daily, working on projects and catching up with people. I am now starting to want a bit more structure and stimulation in my day.

I think the main thing is that I am no longer in the breast cancer system. Yet I'm not in the 'back to normal life' stage. I am in the middle, in a transition. On the positive side, I am still buoyed by ending my year on a high/going to France. That trip gave me inspiration that I can live a great life in the future. Now, I just need to do practical and logistical stuff to get to where I want to be. I am really looking forward to getting back into normal life plus a few adventures e.g. I want to travel again next year and get back into my old field of work – international aid and development. I am looking forward to it.

What is helping me:

- **Setting goals for the future.** What do I really want to do? And stepping gradually towards them one step at a time.
- **Don't forget to focus on health.** I am still in the recovery phase so my health requires attention – exercise each day, eating well, getting back to my pre-breast cancer weight and not over-committing myself.
- **Still getting support.** Art therapy, acupuncture, herbs and vitamins, eight hours of sleep, talking to supportive people e.g. the local Cancer Society and friends.
- **A gentle re-entry to 'normal' life:** working part time or having flexibility, not taking on too much stress at work, having time to exercise and relax etc.
- **Starting to take more risks.** I don't have to live inside a comfort zone anymore. I can start to plan more, socialise more and step outside the box.
- **Being flexible.** Over the past 18 months, I had ideas on what I would be doing now or in my future e.g. where I would be living and what kind

of work I would be doing. Now that I am here in November 2012, I find that my goals have shifted and I am seeking a bit more stimulation and challenge in my future. So I am listening to my intuition more and trying to keep up with new dreams and goals that are coming into my thoughts.

## Moving to a new purpose

NOVEMBER 11, 2012



Recovery from breast cancer is an interesting business. There are lots of twists and turns. So this week I have tried to make lots of things happen and eventually realised, that it was not quite the time for those things to happen (as nothing happened).

Finishing breast cancer treatment is great, don't get me wrong. And being told I'm cancer free is also fabulous. I am very grateful and realise that I am better off than many. But I didn't realise that I had become so immersed in the non-normal world (the cancer world) and that venturing out in the normal world would feel so frankly un-normal. It takes time to transition from the ill world to the healthy people world.

I have realised that 'being normal' doesn't happen just because I click my fingers and say it is so. There are a few things to work through and it is another journey. The big picture is that I am here. I have survived breast cancer and I am alive and stayed sane through all of that. It is a huge achievement.

My purpose for the last nearly 18 months was to survive breast cancer and I put most of my energy in to that. And suddenly, it is time for a new life purpose. I'm not quite sure what it is. I have a few ideas but nothing concrete and to be honest, I hadn't thought about it very much until now.

The other thing is that I have a clean slate. I could do anything now – get a new job, study, travel, new hobbies, move cities or countries. It is exciting to think

of creating a new life. But it is also a bit overwhelming and I don't have too much intuition about where and what I want to do. Some of it may be fear (what if I make the wrong decision?) and some it is just confusion (there are so many options so I need to make lots of decisions). And I just don't seem to have too much energy for new things right now. Which country, which city, which job, how many hours, etc. Each decision requires quite a lot of thought.

I have realised through talking to someone who knows about these kinds of health transitions that there is no perfect decision. And perhaps it is time to try little bits of things and little bits of that in order to decide what I want to do.

So for now, my new purpose is working out what I want to do and how I want to live in my new post-breast cancer life. It is quite an exciting purpose. There actually are lots of options and things that I want to do.

This weekend, I had a migraine very similar to all the migraines I had in the last year. It was interesting as it took me back to how ill I felt only a couple of months ago. I am still healing and recovering and it is a process. It wouldn't be right for me to jump right into a full time job right now. A part time job will be great in the new year. In the meantime, I have a couple of months to think about what I want to do in my life. I will re-read Phil Kerslake's *Life, Happiness & Cancer* book as he has an excellent chapter on doing a life audit and working out what is next.

The goal now is to relax and enjoy life here and now, to do a bit more exercise, eat well, hang out with friends and family and take advantage of some spare time.

## Nearly four months on from Herceptin

NOVEMBER 27, 2012

It is almost four months since my last Herceptin treatment and things are starting to improve a lot.

In the first six weeks, I felt nothing much about finishing treatment, especially as I still had all the treatment side effects. My oncologist said it would take around three months for the medications to leave my system and I found this about right; at the two to three month mark, I felt a heap better.

### Positive steps

I am noticing more physical energy and increased mental energy too (I can concentrate better and just a feeling of being mentally stronger). I am doing a bit more exercise each day and often going for a 45 minute walk on the beach first thing in the morning now that it is light and summery. Somehow, I have lost 7kg. I'm not completely sure how but I think it's a combination of the medications leaving my body, being more active (due to less headaches) and not eating treats (that I felt I needed when I was feeling yuck so often).

### Nearly back to work

I am mentally preparing myself for getting back in to the workplace. I often go to the library for four hours at a time, writing, doing bits and pieces of work-like tasks to get myself into work mode again. I saw a career counsellor last week and went through a range of options for me to try for my re-entry into the workforce. I am looking forward to my new job.

### Projects

In parallel, I have had a few projects on the go. I am looking to improve the Breast Cancer Nirvana website so that is exciting. I have been looking for a new place to live and nearly have that organised. Even though I am not in a traditional

job, I am working on a number of different projects: good health, finding a home, Breast Cancer Nirvana and finding the right job. There are a lot of options around at the moment. From one side, there is not much happening but from my side, there is lots going on.

What has been working for me:

A consistent focus on my health and recovery:

- **Daily exercise** as a priority. Walking each day and doing qi gong. I hope to start cycling again soon.
- **Eating well**
- **Putting myself first.** Listening to my body and reducing stress where possible.
- **Acupuncture weekly.** I have been able to get over colds and headaches quicker and each week, feel that I'm actively improving my health.
- **Herbs.** Taking post-cancer herbs and supplements.
- **Art therapy.** I still find this useful, especially when going through transitions.
- **Career counselling.** Looking at what I really want to do and how to get there. In Wellington, I saw Sue Mortlock who is very good.
- **Friends and family.** Lots of chats and outings with good friends and family.
- **Pace.** Reminding myself of what I've been through and to take things gently. Looking for part time work initially (three or so days a week) as I build up my energy levels.
- **New goals.** Setting new short, medium and long term goals.
- **Keeping busy.** Having a few projects to focus on e.g. the website.
- **Good things** to look forward to – celebrations and weekends away with friends, visiting other parts of New Zealand and planning next year's holiday.



# December, 1 year post-chemo

## Returning to work

DECEMBER 5, 2012

I have had great progress in the last weeks. Firstly, I have found somewhere new to live. Secondly, I am returning to work part time. Things are starting to come together for me and apparently, all at once.

I am returning to my previous employer working 3.5 days per week and start next week. I feel really ready to be back working and I'm looking forward to it. It will be great to be back in a working structure during the day, see my old colleagues and to bring some money in.

I am really glad that I stopped working during cancer treatments. In many ways, I had no choice as I just didn't feel very well during chemo and Herceptin. I feel that I rested really well and it has meant that my energy is coming back quickly.

It will be a challenge to integrate all the healthy activities I've been doing with a busy work environment. I'm conscious that I need to keep my stress levels down, keep my exercise up, eat well and basically keep as healthy as I am now while working. I am only working part time so I hope that I can keep that balance.

### A New Year

There's a nice energy around at this time of year. People are excited about their Christmas holidays. It's summer and we are starting to have long summery days. It's also a good feeling to end one year and start again with a fresh, new year. I am looking forward to 2013 and all that it brings.

2012 has been an amazing year though full of lows and highs. The lows mainly being feeling ill for quite a bit of the year. I think the highs have been launching Breast Cancer Nirvana and having a holiday in France.

## 2012...what a year!

DECEMBER 28, 2012



Photo by Josie Schoonerderwoerd

As we near the end of 2012, I find it useful to review how life has gone, acknowledge the learning and to be grateful for the ups and downs and ...then set some new goals for 2013.

So here is how my 2012 went. Thanks for your support in 2012 and I hope you have enjoyed or got something from Breast Cancer Nirvana.

### What went well in 2012? What needs to be celebrated?

- I finished off all my cancer treatment and then was declared cancer free. What an achievement.
- Staying sane after two diagnoses.
- I put quite a bit of energy into Breast Cancer Nirvana and the site is going well.
- A volunteer team helped to launch Breast Cancer Nirvana and we raised \$5,500 for the local Cancer Society (with the help of kind donors).
- I did some public speaking, radio and TV interviews and did okay (normally, I'm quite shy about these things).
- Lots of new friends and people in my life.
- In September, I decided to end the year on a high note and went to France.
- Helping my body out a lot by eating well, exercising, doing herbs and acupuncture.

### What were the challenging bits?

- Side effects from treatment. Just feeling not great. For most of 2012, I had headaches and migraines five days out of seven. I struggled to cope with the migraines in particular and tried just about everything.
- I gained quite a bit of weight with all the treatments.
- Accepting a life with cancer and cancer treatments is not easy. Also realising my identity was tied up to my job so it was good to learn that I am valuable, regardless of my career.

### What helped me the most with breast cancer and treatments?

- Weekly acupuncture
- Body therapies – chiropractor, osteopath and massage (to help with the side effects)
- Talking and support – [art therapy](#), EFT and talking to wonderful support people.
- Rest – sleeping 8-12 hours each night
- Exercise – every day if I could. Walking, cycling etc
- [Pink Pilates](#) – tailored treatments post-surgery and chemo
- Friends who could talk to me about cancer and talk to me about other things too.
- All the care packages and treats
- My family – being able to stay with my parents when I needed to
- Support people and company to medical appointments – thanks to all my friends and family who helped out.
- The New Zealand [Cancer Society](#) supported me in all my endeavours
- Doing a cancer retreat with [Jasmina Kovacev](#)
- Weekends away, treats here and there...doing as many fun things as I could.

### What I learned?

- Many things! That life is not about work. Not working was really good for my recovery.
- That I can manage a website and contribute to others in this way.
- I can survive cancer and my mind and body can recover too.
- Life is really about dancing in the rain! If we wait for the good days to come, we can be waiting a long time. But each day, we can do something fun even when we feel crappy.

### What I'm most grateful for:

- So much support from family and friends.
- And a crazy good medical and cancer support team – oncology, plastic and breast surgery team, nurses and the local Cancer Support Organisation.
- Healing quickly. The migraines more or less ending about a month after I finished treatment.
- Being able to go to France. That was a game changer for me – I realised that life actually can be good.
- Being able to end 2012 with a bang – moving house and starting work – after four weeks in France.
- Having options with my life and being able to not work for nearly 18 months.
- Breast Cancer Nirvana kept me sane while contributing to others.

### Where to for 2013

I would like to explore:

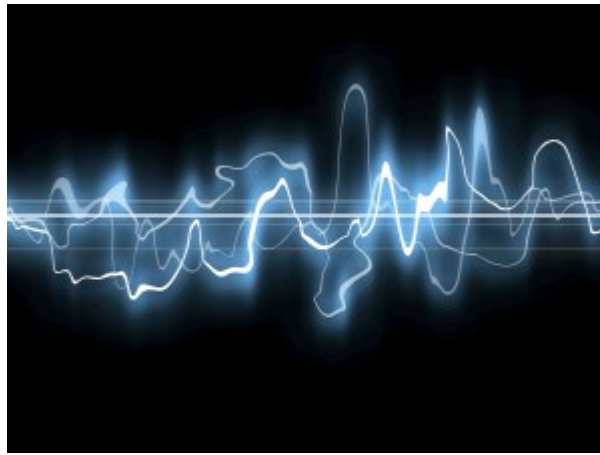
- Doing more travel especially in Europe.
- Living life a bit differently than I have up until now...trying new things and treating life more as an experiment.
- Building up Breast Cancer Nirvana with a team approach.
- Living healthfully – eating well, exercising and keeping a good work/life balance.

# 2013 Chemo Diary

February, 14 months on from chemo

## Post-treatment to the 'New Normal'

FEBRUARY 20, 2013



I just realised that it is six months since I finished all my treatment. And things have changed a lot! Things are starting to hum along nicely and...it is hard to believe that I was a cancer patient.

Yesterday, at work, I felt that I was in the zone. Going to meetings, writing emails, discussing complex issues and it is like the breast cancer chapter(s) never happened. It is usually when I get home that the fatigue hits and I re-remember that I need to treat myself with gentleness. I am still in recovery.

Sometimes I feel I travel between two parallel universes – going to work and being fine and then outside work, dealing with everything that a post-breast cancer life holds (check-ups, side effects, memories and uncertainties). Though at work, the parallel universe intervenes as I notice people working long hours and powering ahead and upwards with their careers. I don't have the luxury of that at this point in my life.



Since August last year, I have:

- Stopped having migraines and headaches for five days out of each seven days!
- Lost nearly 13 kg! And bought lots of new clothes.
- Bought a house that I love. It is a 1970s baby with lots of wood, orange Formica with brown flowers, brown geometric shaped lino and macramé light fittings. It is a five minute walk to the beach which is the best part.
- Spent nearly a month in France on my post-treatment holiday and LOVED it. I would love to live in Paris one day...
- Started working again – initially at 3.5 days per week and now at 3 days per week. Re-established relationships with my colleagues again and got my head around policy and project and programme management.
- Kept up with Breast Cancer Nirvana and I'm still enjoying it.
- And continued to be cancer-free!

Life is still not easy all the time with a lot of side effects still remaining from treatment but in taking stock, I have done pretty okay.

### Work

I have reduced my work days and am working three days (and have four days off). The balance has shifted a bit and I feel more in control of my health (though with a bit less money but hey, I have to put my health first).

I still have a lot of fatigue but with the rest days, I seem to be able to get through. I also have a whole week off next week. Overall, I feel like I am turning a corner in coping with work.

I am pleased with my progress at work. I feel that many of my thought processes and outputs are as good as pre-treatment days. My relationship management, financial management and project management skills are good. I still



find very technical writing the most difficult since all the treatment but I am doing okay.

I feel that my confidence is returning and I am starting to see interesting things in each day (without having to think about breast cancer regularly). Things are settling down to a new normal.

### Health

My headaches have reduced a bit and I haven't had a migraine for a month or so. My hair has been falling out but perhaps a little less. It apparently is stress (not anything more sinister) so I am focusing on reducing those stressful things. I am finding sleep quite hard; winding down after work is quite difficult.

I don't do much socialising these days. Maybe three social activities a week. I am often too tired and then can't catch up unless I take a lot of rest outside work.

I do exercise each morning before I go to work. In general, I'm too tired when I get home from work.

### Medical appointments

I had a check-up with my plastic surgeon this week. It was all fine and I am scheduled for another check up in a year.

I had a mammogram a few weeks ago and I have a check-up with my breast surgeon in a week or so. I expect that to be okay but there are always aches and pains that seem suspicious until given 'the okay' by the specialists.

### What is going well:

- Weekly **acupuncture**
- Post-cancer **herbs**
- Talking to the **Cancer Society nurses**
- **Friends and family**
- **Working** and getting challenged and participating in interesting things

- **Having colleagues** once more. It is great.
- **Things to look forward to** e.g. holidays, mini-breaks
- Lots of **sleep** – 8 hours a night
- I'm **eating** really well – lots of vegetables/salads
- **Exercise** every day – before I go to work (cycling, walking and yoga)
- **New hobbies** – redecorating my house and garden and learning a little French
- **Having income** once again
- **Planning my next holidays**

March, 15 months post-chemo

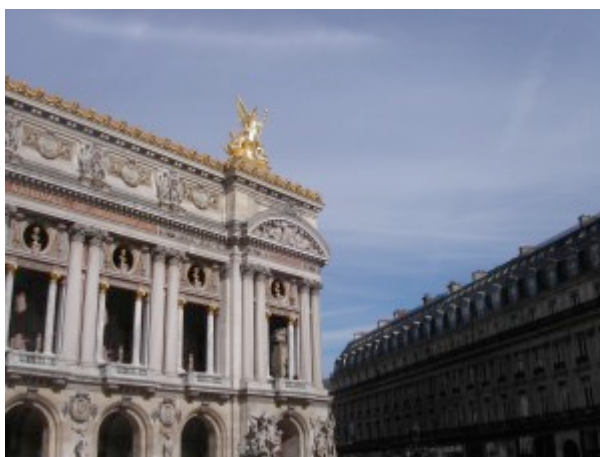
## Snakes and Ladders

MARCH 5, 2013

### Going up the ladder and down the snake

Since I started working again in mid-December, my hair has been falling out quite a bit. In February, I had a blood test to eliminate any thyroid issue (phew, no problem there). So the answer is... stress. I am gradually getting used to the new work lifestyle but I do find it hard to balance work and health. I know everyone does, but when recovering from an illness and trying to prevent illness, I want to make sure I am eating well and exercising... and not stressed. Well, that is the goal.

There is no straight out solution, but I am getting used to work and have reduced my work hours to three days a week. I have also reduced lots of activities outside work in order to keep a balance and the fatigue at bay.



### A Snake

A couple of weeks ago, the nurse at my doctor's office rang me at work. Apparently the recent blood test showed that I have pre-diabetes. That was such a shock as I am living quite a healthy lifestyle. Last week, I went back to the doctor and nurse and the facts are: I will have a repeat blood test in April and if that

blood test continues to show such high blood sugar levels, they will say that I have diabetes. After the initial shock wore off, I decided that it was just a label and an opportunity for healing and being healthier. My doctor said to eat a little bit better and to exercise a little bit more. The nurse thought I was eating and exercising well enough and just to keep going with that.

So...another health issue to address but after breast cancer, I am not too worried. My body has been through so much and apparently chemo can affect the pancreas a little. So there's no blame... just hopefully my body will heal quickly.

### Women's stuff...

And then...after six years, I got my period. I haven't had one since my breast cancer diagnosis in 2007. The shock and then the chemo gave my ovaries quite a battering. Then being on hormone therapy for nearly five years! It is quite a relief to know that parts of my body are going back to some semblance of normal.

### Other than that

My energy levels are coming along quite well. I still have headaches now and then but having weekly acupuncture really helps. As does exercising each day plus eating lots of vegetables. Life is going on quite well apart from a few snakes.

## My annual check-up with my breast surgeon

MARCH 12, 2013



Last week, I had my annual check-up. I had a mammogram in February and this appointment was to go over the results of that, have a breast check up and talk through any issues.

I planned a few points to discuss. I keep a notebook just for medical appointments so everything is in one place. A week or two before the major or annual appointments, I jot down things I'd like to discuss (it is really hard to remember everything on the day). I also take notes during the appointments. I sometimes take people with me to these appointments; it depends on how I feel and whether I feel that I need support or not.

### On my agenda

My agenda items were:

- Results of the mammogram
- Hair loss – any advice or links from the breast cancer treatment
- Having a period – any risks from the elevated estrogen
- Pre-diabetes – any advice or links from the breast cancer treatment
- Where to from here

### The appointment

There was a student present. In principle, I am happy for students to sit in at most of my appointments. However, on reflection, it does change the dynamic of the appointment somewhat and usually feels more formal. I have been seeing my surgeon for six years but with the student, I didn't feel too relaxed.

### Our discussion:

- Firstly, the mammogram was completely clear. That is great.
- The surgeon did a breast examination including an ultrasound and said there was nothing abnormal in either breasts. I have had some pain in my left breast but there was no issue there. In between my breasts, there is a slight thickening but it is nothing to worry about (and we wouldn't want to do more surgery there as it would interfere with the blood flow to the right breast).
- With the hair loss, there is no magic cure and no link with the breast cancer treatment. It should be treated on its own merits.
- On the recent period, the surgeon said it was called a post-menopausal bleed. It could genuinely be a period but may be something else and needed investigation with a probable ultrasound. The surgeon did not think there were any risks from the elevated estrogen levels from having a period.
- With the pre-diabetes, the surgeon said it should be treated on its own merits and had no link with the breast cancer treatments.

It is interesting that there is no direct link between these things and the breast cancer treatment as intuitively I feel that they are all connected. Even though overall, the appointment went well, I came away feeling a bit confused and upset. These types of appointments bring back lots of different emotions and

even though it might be just a check-up to a specialist, it takes up lots of emotional energy.

#### Where to from here:

I will continue with annual check-ups and have met with my doctor to discuss the post-menopausal bleed. She did a smear test and has referred me for a pelvic ultrasound which I'll have next week. It is also interesting to note that taking Tamoxifen can cause endometriosis type issues down the track.

Life is a little daunting at the moment but not on the scale of breast cancer. Just more steps on the road. Outside all the medical stuff, life is going well and I am feeling overall healthy. I still have headaches from time to time but am feeling quite good mentally and physically. Working three days per week seems to be a good fit for my health and recovery (though financially, it's hard to take the reduced income).

#### What is helping in my recovery:

- Weekly **acupuncture**
- Having **medical specialists** that I genuinely like and feel comfortable with
- **Having one notebook** for all my medical appointments (agenda items and noting the discussion)
- **Support from friends and family**
- **Working part time** – not too many hours but I'm enjoying the challenge of work and the social side of working
- **Talking to specialists** at cancer support organisations including their nurses
- **Exercise** every day, eating really well and lots of rest time
- **Losing weight** is making me feel better

- **Having hope** for the future and plans for enjoyable things to look forward to e.g. a holiday
- **Writing my journals** for Breast Cancer Nirvana



# April, 16 months post-chemo

## Lots of medical stuff

APRIL 7, 2013



A lot of simply normal things have been going on including a cold bug that lasted far too long, going to work and getting lots of things done on my house.

### Tamoxifen consequences

I never really thought about taking Tamoxifen when the specialists recommended it. I didn't mind taking it at all as for me the side effects were so much better than Femara (terrible joint pain). So who knew that years later, I would have issues due to Tamoxifen causing endometrial thickening.

My doctor recommended I have a pelvic ultrasound. That was okay except for needing to drink one litre of water in half an hour (while at a work meeting) and not being able to go to the toilet until around an hour later. Fortunately, the ultrasound was clear. There are no polyps and my ovaries look fine. However, my doctor has referred me to a gynaecologist for follow up including a probable procedure. Interestingly, this all doesn't bother me too much.

### Pre-diabetes

On the pre-diabetes front, my doctor has prescribed a diabetes medication. I will have a blood test next week to check my blood sugar levels (and use this as a baseline) and then start taking the medication. Interestingly, this does not faze me too much either. As we know, there are worse things in life. However, I am aiming to lose another six to eight kilos in the next six months and improve my mainly vegetarian diet with more vegetables, more protein and less sugar.

### Moving On

I have noticed that out in life, I forget more and more about breast cancer. It is so reassuring to know that things never stay the same. I had breast cancer but it is part of my past.

Side effects from the breast cancer though are still part of my 'now'. I still have fatigue, headaches and lots of medical appointments. But fortunately, the side effects are nowhere in the same league as a year ago.

### Work

It's great that I am working three full days a week. I am enjoying working and being out in the world. It took me around three months to get back my pace at work. I wouldn't want to try doing four days a week yet, but hopefully I will by the end of the year.

Working part time does have impacts financially but I simply need to wear the financial cost as I don't want to wear myself out instead.

### What is helping me in recovering from breast cancer:

- Weekly **acupuncture**
- Great **friends and family**
- **Lots of rest** when I need it
- **Daily exercise**

- **A great team of medical specialists**
- Seeking **nutritional advice**
- **Things to look forward to**; hopefully a trip at the end of the year

## Diabetes, surgery and media

APRIL 19, 2013

Life is always a series of highs and low. This week, I experienced an unusual high. After being told I had pre-diabetes a little while ago, my latest blood tests revealed that my blood sugar levels are normal. I was rapt; I have lost a kilo and am watching my eating more than usual. I had hoped that the pre-diabetes was a blip and perhaps it is. My doctor though still wants me to lose more weight and to take the diabetes medication to do that. I do feel a lot better with less weight.

This week, I also saw a gynaecologist as follow up for the post-menopausal bleeding. She has scheduled a procedure for the 8th of May. Basically, the procedure involves taking tissue from the uterus to rule out uterine cancer. Mainly the thinking is still that this is a side effect of taking Tamoxifen. My gut feeling is that there is no uterine cancer but as we know, it's good to cross the t's and dot the i's.

Then, I had a migraine mid-week; I think just too much going on all at once. That is a lot of medical stuff. Meanwhile, I do feel quite healthy and have a parallel life, at work. I am feeling more and more in my stride at work, gaining back all the confidence that I had before and starting to think about what I want to achieve career wise.

This week, I was called by a journalist from Radio New Zealand to be interviewed on the about an increase in the amount of Pacific Island women taking up breast screening which is great. I was sitting in the waiting room to see the gynaecologist and did the interview on my cell phone. I am starting to feel more comfortable in doing these kinds of things. I also had an interview with the Kapiti Observer. I am starting to see that there is quite a need for advocacy to help reduce Pacific Island breast cancer statistics.

What has been working well for me:

- Having weekly **acupuncture**.
- **Eating really well** – lots of protein and vegetables – and exercise daily.
- **Being at work** and connecting with colleagues though the week.

**The Kapiti Observer article:**

## **Cancer survivor's website wins unsung heroes prize**

by Joel Maxwell



It was during chemotherapy for her second case of breast cancer that Andrea Fairbairn, 45, took up a hobby: web master. Andrea Fairbairn has created a website offering support to those with breast cancer. Enrolling in a website design course gave her something to do – and, she realised, there was no shortage of content for the site she planned to create.

Last week Ms Fairbairn spoke to the Kapiti Observer about her website offering support for people with breast cancer, created while she confronted the disease for the second time in four years. Ms Fairbairn, who grew up in Kapiti, said she was first diagnosed in 2007 on her 39th birthday, an announcement that came out of the blue.

“It was a real shock. You know you get an intuition about things sometime? I had no intuition at all about it.” After surgery, chemotherapy, radiotherapy and drug treatment with Herceptin, she was declared cancer free.

Her website launched last year as she pushed through treatment for a second bout of the disease, diagnosed in 2011. The website, [breastcancernirvana.co.nz](http://breastcancernirvana.co.nz), was part of a different approach to the experience for Ms Fairbairn.

During her first cancer she kept working at her job with Ministry for Foreign Affairs and Trade. This time she stopped work, and decided she would help others with what she had learned.

“Because after the first one I thought ‘I’ll just move on, get on with my life and forget about it’.” Ms Fairbairn blogged her experiences which included a mastectomy and breast reconstruction.

It was around the time she found out she would need chemotherapy again that she read about the website course. “I thought maybe I’ll do that and that will give me a bit of a hobby, something different to do . . . by the second week we’d set up a website, and then it was just doing all the content.”

The website shares the stories of breast cancer survivors, and offers practical advice and resources. It won Ms Fairbairn an award for unsung heroes from international group Five Point Five, dedicated to boosting community leadership and travel.

Meanwhile she has been diagnosed as cancer-free again and returned to work in December. She will continue running the website, which she hopes will be part of an important network for people with breast cancer.

“One of the things that I learnt from my reading is that . . . the more support, and quality relationships a person has, the higher the survival rates.”

May, 17 months post-chemo

## New Beginnings

MAY 21, 2013



Things have been going forward quietly and healthfully!

### Work

As I only work three days per week, I am finding it a bit tricky to get ongoing work. I am a bit hesitant to move up to four days a week just yet as I fear I will get overtired and burn out. I have reminded myself that I am still in a recovery year and need to take work gently; health is the most important thing. However, the practical side of this is not that easy. There seems to be lots of work out there but a lot of part time work pays less, and people wanting full time employees usually really want a full time staff member. I have had lots of meetings with potential employers so I am sure something will pan out. It does leave me a bit unsure as to which direction to take but I am okay for now.



## Health

Overall, my health is quite good at the moment. Two weeks ago, I had a small gynaecological procedure concerning the post-menopausal bleed I had, six years after finishing my periods (from chemo). I feel pretty good and just have had a hot water bottle on my stomach and a bit of rest. I am not allowed to exercise for the next month though which feels weird.

I have been encouraged to lose more weight to improve my health and blood sugar levels. I had some good advice from a specialist about my mostly vegetarian diet. He said that I was not having enough protein and recommended 1-2 eggs in the morning, fish 2 x per week, 2 green kiwifruit each day, a carrot and 2 x apples each day, 80% or higher chocolate and a few other things including an hour a day of exercise on a cross trainer. I have been following this and lost another 2kg. I am really happy with my progress and look forward to getting fit again once I'm exercising once more.

## Things to look forward to

I feel that my life has been a bit dry with work, rest and now wintery days. But I have a bit more time for reflection, social life and thinking about holidays. I have met some new people of late and am really enjoying my weekends.

## What is working for me:

- **Acupuncture** weekly
- **Eating really well** – lots of protein and vegetables
- **Losing weight** and buying new smaller clothes
- **Having interesting and social work** but not too much of it
- **Looking at future work projects**
- **Lots of rest** still, when I'm not busy at work

# June, 1.5 years post-chemo

JUNE 4, 2013



Paris from the Eiffel Tower

I have just realised that I have just passed my two year anniversary for the breast cancer surgeries which started in June 2011. It is very cool that I wasn't even thinking about it and too incredible for words, that two years on, I am feeling well and happy. When going through the bleak dark tunnels of surgery, chemo and a bit of despair, it is hard to imagine that those life low-lights were actually just blips.

So much good has come out of the bad stuff and I feel very grateful and blessed:

- My chemo and Herceptin worked; I am cancer free and down to annual check-ups.
- I am happy with the reconstructed breast; okay I have a few scars around the place including my tummy. But overall, I don't think about the breast anymore. I worked hard to get that new breast reconstructed and I feel really good about it.
- After finishing all the chemo and Herceptin, I am physically feeling a lot better. It took a few months to get the medications out of my system and as that happened, I lost weight and gained energy. I think my

immune system is still a bit low and I am not 'high' energy but I feel good.

- I feel that I have a better sense of who I am and what makes me happy. I am now living life more on my terms and listening to my intuition more. I feel that I am finally the Chief Executive of my life.

Since finishing treatment in August/September last year, I have had a one month holiday in France, bought an apartment, started working again and all kinds of other things. By the way, I really recommend doing a dream post-breast cancer holiday. It filled me up with good times, hope, and inspiration which are the perfect antidote to migraines, nausea, needles and hospitals.

### Turning the corner

As June arrives good things are starting to come my way; I feel like I have turned a corner with life. I have finished a contract at work and am looking at a couple of different, new work projects. I have found that even though I finished all my treatment late last year, I still need and want a lot of flexibility in terms of my work and to do with health too. I will keep you posted on the new projects as they arise.

I heard an interview with a dancer on radio recently; she had had breast cancer twice and she said something like "after all of that, I felt that I never wanted to work full time again. I wanted to do lots of different things and I'm a lot poorer but I've had a great life". That is exactly how I feel.

I have had some wonderful connections and conversations with friends lately and feel that those connections are hugely important. I feel that I am moving on to great things at the moment and am feeling really blessed and fortunate.

### Inspiring messages

A good friend said this recently and I think it sums up a lot of our lives:

“When I was diagnosed last year I decided that in 2013 I would travel as a reward for being given a second chance at life”.

A friend Sandra gave me a card this week. It says: “And the day came when the risk to remain a tight bud was more painful than the risk it took to bloom.”

Another friend Sara left me a note:

“You are such an inspiration girl. Keep doing what you are doing and fulfil your purpose and dreams. Life is precious babes”.

I feel that I am on track with my life. It is not the life I lived before (it's a different 'normal') and maybe on paper, doesn't look that great. But it is great for me as I'm doing what I want to do and hopefully making a difference.

I want other women to know that they can get through breast cancer. And afterwards, life might even be amazing...even if it's two years down the track.

## From rain comes sunshine

JUNE 19, 2013

When I started this diary, I wanted to share what it is really like to experience breast cancer, chemo and then move on from breast cancer including the lows and the highs. My goal was to be real and break down some of the unknowns and fears about breast cancer and what life would be like afterwards. And to show women that there is light at the end of the tunnel.

I wanted to show that:

- There is life after breast cancer and survival for the majority of us, at least 85% in New Zealand.
- Healing does not follow a strict linear path.
- Recovery from breast cancer treatments often takes as long or longer than the treatments themselves.
- There are significant needs and issues post-breast cancer; primarily a need for support as many women go in to depression post-treatment.
- There is a pathway and support for all of us; that we all are different but there is support for every single one of us.
- Many people will not understand how you are feeling but there are many of us here who do understand and are here for you.
- Life after breast cancer is confusing; they talk about the 'new normal' and those words do not begin to skim the surface of the enormity of grief, identity, mental health and physical health issues that can surround you at various times.
- Breast cancer is a type of personal development in that as you know yourself more, and realise what life is about and that life is finite, amazing life changes can take place.

- There are many things that we cannot control (e.g. cancer) but there are lots of things we can control (e.g. our attitude, going on holiday, taking new risks and changing things in our life that don't work).



Rainbows by Nicky Fairbairn

Ultimately, I wanted to provide some inspiration and show you that life can be great and even amazing after breast cancer. That you can go forward and live a life you love. I hope I have shown that despite all the snakes and ladders of my life.

# Conclusion

## About me

I'm Andrea Fairbairn and I am a 45-year-old Pacific Island New Zealand woman who's had breast cancer twice.

I was diagnosed with breast cancer in 2007 and again in 2011. From my breast cancer experiences, I wanted to share my vision of making breast cancer easier and a positive life changing moment, rather than all nausea and hair loss.

I have lived most my life in Wellington, New Zealand; though I have done a bit of travelling overseas for work and holidays. I have always loved art, writing and helping people and have a BA in Psychology. I then worked in community development and international aid and have a Master's degree in Development Studies. However, when I was diagnosed with breast cancer, it started me on a whole new direction of self-care, healing and learning.

## About Breast Cancer Nirvana

When I had breast cancer the first time, it was hard and there was so much learning in that time. However, when I was diagnosed the second time, it felt different; I had already learned pretty much all I could learn about breast cancer. This time, I felt that part of the purpose of my breast cancer was less about me and more about helping others... sort of part of my destiny.

So I created the Breast Cancer Nirvana website with this vision, and remain committed to supporting others not only survive breast cancer, but hopefully win a second chance at a great life. The name Breast Cancer Nirvana came about as I wanted people to feel peaceful and supported when they came to the site and also,

to reflect the personal development and growth required through the experience of cancer.

Part of Breast Cancer Nirvana is about utilising my experiences for good by sharing the ups and downs of breast cancer and chemo. There are piles of cool resources, support and inspiring stories for women going through breast cancer and I wanted you to see everything in one place. Also, I wanted people to learn about what it's like to go through breast cancer, and tips on how best to support our friends and family going through breast cancer. Please also check out my e-book Chemo 101, where I go through all my lessons learned and tips for making chemo a bit easier and a bit better.

I wish to thank so many people in my breast cancer journey. My family who have been so supportive, my super amazing medical team and my fabulous friends. I feel very grateful for every terrible and wonderful experience as it has brought me to who I am today, where I am healthy and in a great place.

To find out what I'm doing now, please check out my Moving Forward Diary on [www.breastcancernirvana.co.nz](http://www.breastcancernirvana.co.nz).

X Andrea