



# The Pink Sister's Cancer Journeys

## Introduction

Breast cancer is the most common cancer in the UK. 15% of all newly diagnosed cancers in the UK are breast cancer.

Chemogiftbags is run by a small team and lets people in Berkshire, who have Breast Cancer and are undertaking chemotherapy, know that there are people who care. The team produce gift bags which consist of many items that might make chemo a little more manageable. They include cosy socks, slippers, blankets as well as flavoured teas, word search books, soft tooth brushes, a "Thinking of You" card and many more items. All of the items are donated by the public and by business.

Healthwatch Wokingham Borough commissioned Chemogiftbags to capture stories of those living in Wokingham Borough who have been through breast cancer treatment, to find out about the ease of accessing information and services locally.

## Story 1

I would like to share my cancer journey not to scare anyone but just stating the facts so that others can be prepared for some of the symptoms but would like to reiterate that it does not last forever and the symptoms do eventually subside!

I was diagnosed on 10th Feb 2016. A major shock. I remember crying and not understanding anything that was being said after I was diagnosed. Thankfully my chemo nurse has been an absolute angel and took us to a private room and explained what happens next. She also gave us leaflets to take home to read.

Diagnosis : 10th Feb 2016

21mm grade 3 invasive ductal carcinoma of the left upper outer quadrant, ER8/8 PR3/8 HER2 positive. Ki-57 40% pT2 N0 (0/2 on sentinel node biopsy) M0.

Treatment : 1. Wide local excision, sentinel node biopsy 1st March 2016

2. For adjuvant chemotherapy with FEC, Docetaxel and Herceptin to be followed by radiotherapy and endocrine therapy.

My body's response to the various treatments :

1. 1st March 2016 - Sentinel node biopsy - Severe constipation lasting a week - finally prunes did the trick
2. 13 March 2016 - PICC line inserted.
3. 14 March till 26 May 2016 - 3 cycles of FEC T - severe constipation lasting 5 days, Fatigue, loss of hair after 3 weeks of first chemo, loss of interest in food and water.
4. 14 June 2016 - 1st Herceptin injection. Kept under observation for 4 hours. Came home and suffered with flu like symptoms, high temp, headache, heart palpitations, dizziness taken to AE and collapsed in hospital. Kept in isolation and treated for infection
5. 23 June 2016 - 1st Docetaxel - started rash on hands and feet, lost two thumb toe nails. Poor tolerance to Docetaxel so Oncologist switched to weekly Paclitaxel for last two cycles.
6. 14 July to 25 Aug - weekly sessions of Paclitaxel. Feeling tired but generally ok. My nails started splitting a month after my last chemo. I was also having dizzy spells when my blood count was low.
7. 21st Sept - Fractured and dislocated shoulder. Went to hell and back with pain in my shoulder and unable to drive. Feeling hopeless and helpless and a major setback in my progress.
8. 14th Nov - 7th Dec - 18 sessions of Radiotherapy. First 5 days were in agony trying to hold my arm up. It started getting better after the second week. I have felt fine during the sessions but noticed the skin around my breast has darkened and started peeling and it is replaced by new skin.
9. 14 Nov 2016 for next 5 years - Endocrine therapy - anastrozole 1mg - no side effect.

As scary as all this sounds this was my journey throughout the year. Some days were absolutely fine whilst others were more of a challenge. I want to say to anyone going through this or about to embark on this journey you are strong enough to deal with it, you are a survivor and remember it won't be like this forever !!! The above is just to highlight some of the side effects of the treatment that I went through, it is different for each individual

Every single care practitioner and person involved in this journey has been absolutely incredible and I could not have done it without their help and caring support. I count myself extremely lucky to live in a place with great support networks

**Chemogiftbags** came as a ray of hope for me it was like Santa came early. Having my whole family here when I received it, it shifted my thoughts from having no hope to knowing that people outside of my family were showing their support. I think c **Chemogiftbags** are doing an amazing job of bringing hope and practical support into people's lives when they need it most. It is a great and needed charity for people who are in a bleak situation

## Story 2

"On 19th December 2015, I visited my GP, as I had felt something not right in one of my breasts. I wasn't worried as I hadn't found a lump, but thought I should play safe as my friend's wife was having treatment for breast cancer. Two weeks later I was at the breast cancer clinic and the doctor performing the ultrasound and biopsies told me to expect treatment in 2016. The breast cancer nurse gave me the best advice, she said *"you can't control the thoughts that pop into your head, but you can control what you do with them"*. An hour earlier I had been in tears, but that piece of advice shaped the rest of the journey this year. In the whole 10 months of treatment, there's only been a handful of days which have had tears.

I had a mastectomy a month later in the local NHS hospital, the surgeon and other staff were great. I was very concerned as I've never been in hospital and I have mild Aspergers, so I needed to feel in control enough so I didn't freak out. The surgeon put me first on her list, the breast cancer nurse arranged for me to see the ward a week before the op and they managed to get me a single room. The whole experience was reassuring and the anaesthetists kept my mind off what was about to happen.

When it came to needed chemo and radiotherapy, the oncologist asked if we had private health insurance, which we do, so I was able to go private. I don't know what these treatments are like on the NHS, but the private hospital was great. My husband says he's never been to a medical place where there's so much chat and laughter. Again, being able to have a private room helped a lot, as it meant I could feel in control again. The other big plus was having a Hickman line put in under the skin, rather than having tubes dangling out of my arm for five months. I have horses and cats, and do martial arts, and I would have been worried about the external tubes getting knocked or damaged. Having the line under the skin meant I could carry on with all my activities during chemo, although at a reduced level.

We'd seen the poster for chemo gift bags in our local post office parcel depot. I nearly ordered one for my friend's wife when she got breast cancer, but made her a quilt instead. She was very, very pleased with the quilt and I put lots of positive thoughts and love into making it. But no-one made me a quilt. My mum did crochet a blanket for me, but mums are supposed to do that, so although it's lovely, it's not the same as someone a bit more distant showing that they care. So when my husband saw the poster again at the parcel depot, we decided to ask for one. The contents are great, just what you need for chemo, although we did have a chuckle at the comb, since my hair was long gone by then! But the contents were only part of it, the big part was that someone who didn't need to care, cares enough to put together the bags and deliver them. The contents are all useful, but the mental boost that the bag gives is invaluable. It makes you feel special and loved."

## Story 3

I found a lump in my left breast in August 2015. After going to see my GP I was referred to see a Consultant. My first appointment I was really nervous. I saw the Consultant who said he didn't think it was anything sinister but would send me for a mammogram. I went for a mammogram and had biopsies taken there and then. The ladies were very kind and tried to keep me calm and told me everything they were going to do.

Went back to see Consultant who firstly apologised for wrong diagnosis and told me I had cancer. From that moment on I cannot fault the care and treatment I have received. Everything happened very quickly from lymph node biopsy to Chemo which is a frightening experience. The chemo nurses were all so wonderful. I had to have chemo before my mastectomy to shrink my lump.

My friend got in touch with **Chemogiftbags** and a lovely lady came to my home and gave me my bag. She had been through cancer herself so it was nice to speak to someone who had been through it and was there to support you.

I then saw a wonderful lady surgeon four times before my skin sparing mastectomy- she was so lovely and made me feel comfortable about what was to happen. And a good job she did too! Radiotherapy went very smoothly for me and I had no burn marks. Being told you have cancer is the most scariest thing ever but Everyone involved in my treatment and care have been caring, supportive and very kind. I cannot fault the treatment I have been given.

## Story 4

I was diagnosed with breast cancer in mid January 2015 after finding a lump by sheer accident. I saw my GP who was very thorough and confirmed my findings. She was really calm and supportive and explain the procedure to determine whether or not it was malignan.t I was told I would be seen within two weeks and was initially happy enough with the timeframe and to be seen by the NHS at the Royal Berkshire hospital. Through my husband's employer we have private medical insurance and due to the shorter waiting time I chose to go via that route. I initially felt really guilty about this. I was reassured when a friend suggested that on the going private it would speed up the process for someone else in the NHS.

I was seen within a week and had a mammogram, ultrasound and biopsy, all carried out to my first appointment. This was fabulous to have it all done on the same day. Everyone, including the surgeon, was convinced it was nothing to worry about. The biopsy showed it was cancerous and so I booked the surgery for a lumpectomy for a week later the date of my appointment to confirm the results of the biopsy for one day after the date of my NHS appointment.

Upon a clean removal due to the lump size and micro tumour in the first lymph-node they decided that I would need chemotherapy, as a belt and braces approach. Chemotherapy was booked for several weeks later. I had a Port-A-Cath put in one day and chemotherapy started the next. Lynne from **Chemogiftbags** was fabulous, popping into my home as I came home from the first chemo. Her recollection of me was rabbit in the headlights and this is very apt for how I was feeling. It had only been about six weeks since I first found the lamp and so much it happened.

I can remember the feeling on opening the **Chemogiftbag** and looking all the goodies. It made me feel very special. I love that it was a mixture of items to physically help with what was to come and the items like the sparkly notebook ad Velour scarf, just to make you feel special. It really help me feel that I had some control or at least some tools to fight this.

My treatment had been a bit of a rollercoaster. Chemotherapy itself was very calm and the side-effects well-managed. I was unfortunate to be one of those people whose temperature spiked a week after

each chemo. I found myself having to seek medical advice 5 out of the 6 times. For most of these I went back to Dundine in but one was via the Royal Berkshire hospital. In all cases I was very well cared for with the Royal Berkshire hospital could not access the port and had to use peripheral veins which was very difficult.

The Port-A-Cath had been great to access for chemotherapy. Despite the operation to insert it being very stressful. I have realized how lucky I am to have had this rather than trying to access veins, as my veins are very tricky to find. I would not change anything about my treatment journey and have been kept well informed every step of the way and completely involved in my treatment decisions where appropriate information has been given to me in bite-size chunks and support available throughout

Just as important to me, has been joining the **Chemogiftbags** Facebook support group this has been invaluable to me throughout chemo and radiotherapy and beyond. There have been several occasions where I needed advice or friendly support late at night and it was always been so positive and helpful. I particular remember the night my hair fell out, in a panic I felt I wrote a “cry for help” message very late, by morning I had several messages of support. This is such a fabulous group of women. One lady I met recently said to me that the group was so lovely, it's just a shame that the price of it she was so high. I've been lucky to enough to have my own group of friends but this group really adds to my life. I've met some great people I felt that this is a lovely charity and I'm keen to get involved in raising awareness in supporting the teams in as many ways as I can.

## Contact

If you would like to find out more or possibly donate some items <https://www.facebook.com/Chemogiftbags/> by email [Chemogiftbags@outlook.com](mailto:Chemogiftbags@outlook.com)

**healthwatch**  
Wokingham Borough

[www.healthwatchwokingham.co.uk](http://www.healthwatchwokingham.co.uk) 0118 418 1 418