

## Lynette McHendry's Story



'In July 2015 I visited my GP with a pain in my left breast. I was referred for a mammogram at which stage I was told that it was glandular and nothing sinister, however the mammogram had detected a small lump in my right breast. Following a biopsy I was diagnosed with breast cancer in my right breast.

Following my lumpectomy while recovering from surgery the pain in my left breast continued as well as the breast getting larger, hard with dimpling and hot to touch.

Concerned about my symptoms I had googled as we all do and seen they matched a breast cancer called Inflammatory Breast Cancer. I had never heard of this before but reading the statistics of low diagnosis and poor prognosis I thought I wouldn't like to have that.

At my initial appointment with oncology to plan chemo I mentioned the symptoms I had on the left side. I was referred back to the breast clinic for a biopsy which confirmed I had cancer on my left breast too.

Four hours after being told I had breast cancer in my left breast and was now at a different stage and would need a mastectomy after 6 rounds of chemo. I was hooked up to chemo. While reading through my notes the chemo nurse said "oh you have the Inflammatory type". This was a huge blow to me as I remembered everything I had read about Inflammatory Breast Cancer.

I read a lot about Inflammatory Breast Cancer over the following weeks and joined a few forums on the web. I found Inflammatory Breast Cancer Network UK which was a small support group for women diagnosed with Inflammatory Breast Cancer there were 110 ladies on the group.

I discovered that there was currently no specific research being done on Inflammatory Breast Cancer due to the low diagnosis in the UK. Caroline Sands who started the support group had informed me a Dr in Birmingham University intended to conduct research however this required funding. This is when I decided I would raise much needed funds as well as raise awareness to other women of the symptoms of Inflammatory Breast Cancer.

As a woman I believed that a lump was the main symptom of breast cancer, however Inflammatory Breast Cancer does not have a lump. I also learned that breast MRIs are more appropriate for diagnosing Inflammatory Breast Cancer, however a simple biopsy would also determine cancer.

I know a lot of women diagnosed with cancer want to keep it very private, however I felt I needed to get awareness out to women about the symptoms of Inflammatory Breast Cancer as it is so aggressive any delay in diagnosis could be the difference of life and death.

I went public by contacting BBC Newsline and being interviewed for a TV and radio report. I then put a fundraising plan in place to raise money for Birmingham University all while I was having chemotherapy a double mastectomy and Radiotherapy.

After 9 months of fundraising activities I was able to handover £28k to Inflammatory Breast Cancer Network UK which was then handed over to Dr Berditchhevski of Birmingham University to initiate research in this aggressive breast cancer.

I have provided support and advice to many ladies diagnosed with breast cancer not just Inflammatory Breast Cancer through people asking me to talk to friends or relatives diagnosed. In my previous life as a civil servant I would be required to communicate with all levels of people therefore have been the voice for ladies who would not have the confidence to question their diagnosis and treatment plans.

At every opportunity I tell people about Inflammatory Breast Cancer. I don't refer to it as Breast Cancer as I want every women to know of the very different symptoms than a lump. I have been surprised by the number of health practitioners who have never heard of it. I met with my surgeon to ensure lessons be learned on my misdiagnosis to ensure it does not happen again.

I started a blog to tell my story which unfortunately did not end after my primary treatment as it unfortunately spread to my brain. So far I've had 3 tumours removed from my brain and had 7 months of 2nd line chemo for spread to the lymph nodes in my neck and collarbone.

My aim is to give women a voice, emotional support and practical advice from my own experience over the past 3 years. My main advice to women is never ask for a prognosis and do not look at the statistics as I am walking evidence that you can defy the odds if you put every ounce of hope and willingness into living rather than dying.'

**Lynette McHendry**

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