



### **My story. Caroline Swain. Essex, UK**

Hi, I'm Caroline and have agreed to tell my story about my experiences and feelings with regards to my cancer diagnosis and treatment, in the hope of helping others, who may find themselves in a similar situation. My story started ten years ago in April 2002.

Just before I turned 35, Rowland and I had our first son, Max. We loved being parents and decided to try for another baby. When Max was twelve months, I was diagnosed with breast cancer. The consultant asked if I was likely to be pregnant, I didn't think so, as I was only one week late. At that stage, it was thought that I may not be able to go through with the pregnancy, had I been pregnant.

The day before I was due to go in to hospital for my pre-op tests, for a lumpectomy, I did a pregnancy test.....it was positive! Rowland and I did not know how to feel.

On discovering that I was pregnant, my treatment had to be reviewed and a meeting with my surgeon was made. I felt a panic inside my body and found it extremely difficult to keep myself together; we didn't know whether or not keeping the baby would be an option, we didn't know whether or not I was going to die. There were too many emotions to cope with; my life turned to a sort of numb 'auto pilot'. Rowland and I did not tell anyone about the pregnancy; we did not know what the outcome would be and we did not want to give our family and friends even more concern than they already had with regards to the diagnosis of cancer. We were left to face the devastatingly sad thoughts of whether the pregnancy would have to be terminated? Will I see Max grow up and will he remember me? Anger also filled me, how can it be that at the age of 35, my life expectancy for the next 5 years is seriously put to question? I was scared and distraught.

My emotions ran riot. I was surprised at how strongly I felt with regards to the lengths I was prepared to go to save our unborn child. The urge for me to save our

baby's life was stronger than saving my own. There was no joy at being pregnant, but fear for the unknown.

Thankfully, we did not have long to wait until my surgeon and oncologist had thoroughly researched what the latest treatment options available would be to me. My consultants were extremely supportive. It was decided that I would have a radical mastectomy and lymph node clearance the following week and chemotherapy, once I had finished my first trimester of pregnancy at 12 weeks. A minimal amount of anaesthetic would be used for the surgery, to reduce the risk of miscarriage. Due to the aggressive nature of the cancer, it was decided that it would be best for me to have a radical mastectomy, rather than having a lumpectomy with the likelihood of needing a further operation to remove more tissue; two operations would pose a greater risk to miscarry.

Our parents were extremely supportive and looked after Max whilst Rowland and I went to numerous hospital check-ups and visits.

Once we knew that it was possible to keep the baby, we eventually told our families and friends. People didn't know how to react. Some were concerned for me, that my chemotherapy had been delayed, some were concerned with regards to the outcome of the pregnancy; would the baby be normal or even survive? Or others just had no idea and were over the moon for us, as if it were a normal pregnancy!

I was absolutely distraught about having to have chemotherapy. I rarely took a headache tablet, so the thought of chemotherapy was repulsive and scary to me and this was emphasized by the fact that I would be having this whilst pregnant. I felt all sorts of emotions. I was desperately trying to get the answer with regards to how having chemotherapy, could be possible; how could it be possible to have these drugs whilst pregnant? How could it not affect the baby? I had no choice other than to trust my consultants.

Eventually, I got the answer that made sense and that I could accept (I ask a lot of questions and am interested in understanding the medical details). Certain drugs do not pass through the placenta to the foetus. Our bodies are amazing!

This all took place 10 years ago now. On 15<sup>th</sup> January 2003, I gave birth to a healthy son, Luke, at full term and naturally (even having had an emergency caesarean with Max). Luke is developmentally and physically healthy.

The emotional and psychological effect it has on one is not talked about much. The priority of course is to be treated clinically but the mental impact is also phenomenal. After 5 years, when my boys were both at school, I plucked up the courage to call the cancer counsellor at the hospital. It was such a relief to be able to talk to this lady and be reassured that what I'd been going through was in fact normal and she understood completely.

My emotional state had been heightened over the years due to my anxiety of death. When on various occasions, I was terrified that the cancer had come back, I had various scans to reassure me that it hadn't (two dads in Max's year died of cancer, one of which was a friend of ours). Anger started to build up inside; I started to wake up in the middle of the night petrified because I couldn't breathe (I later discovered that these were panic attacks). I would lie awake, in bed at night, being cross with myself for eating, for example, a bar of chocolate, as I felt that I hadn't done everything I could, to give myself the best chance of survival.

In order for me to deal with these emotions I needed to understand them. I went on various courses run by the NHS (National Health Service), which didn't quite hit the spot, but was able to take what I needed from them.

Much of this could have been avoided had I spoken to a cancer counsellor sooner or met up with a cancer support group.

Even though, when I was first diagnosed I would tell friends how I felt and talk about my treatment, after a while I stopped talking about it. Once a year has gone by, people seem to assume that all is back to normal. Although we were delighted and relieved that Luke was healthy, I was scared that the cancer would come back. I used to look at my lovely sons and wonder whether I would see them grow up and whether they would remember me.

In hindsight, I realise that accepting help offered and even asking for it, is crucial, as is trying to understand

one's emotions – to talk about how you feel with someone who understands.

I now know what it means to look after oneself both physically and emotionally. The fear is still there, but it has faded and I have learned to live with it. Rowland and I treasure our family times together even more now.

In November 2010, I was delighted to discover, on the internet, a medical paper detailing Professor Amant and his team's findings, with regards to cancer treatment whilst pregnant.

I went straight to their cancer in pregnancy website and contacted them in the hope of finding someone else, who had gone through a similar experience and in the hope of contributing to their research. It was extremely important to me that the successful cancer treatment that I was given, was documented, so that this could be used to help others.

Luke and I now go to Leuven every 3 years. We have turned it into a positive; we very much enjoy our visits, they are an adventure and Luke is becoming an expert in biology! It is of course, also, very reassuring to confirm the fact that Luke is mentally and physically healthy and to have this long term outcome of the children (who were in their mother's womb during cancer treatment) documented for future generations.

