I went to see one of our friends, who is a surgeon, a week later as it hadn’t gone away. He examined my neck and said that the swelling was coming from the left side of my thyroid gland, this prompted him to ask if I had a history of thyroid problems. I didn’t, he took blood to check my TSH and sent me along for an ultrasound scan. The radiologist took ages doing the scan on the left side and I started to wonder if something really was wrong. He said ‘You have a tumour in your thyroid, most probably nothing to worry about but we won’t know for sure until you have it out!’ Hmm, I didn’t like that word, I knew most tumours were benign but that’s when I began to realise that all may not be well.

I saw a surgeon three days later, he told me I had a ‘considerable mass’ in my neck and that although nine out of ten of these lumps were benign, I was in the right age group for this to be cancer (oh crap). He did a fine needle aspiration of the lump and sent it off to the path lab. Surgery was scheduled for four days later, we cancelled our summer holiday which was due in two weeks. The needle biopsy came back inconclusive and my surgeon explained that I would have to have only the side of my thyroid gland removed with the tumour initially, if I did have cancer I would need a second operation to remove the other half (great). The first operation was ok, the first night was a bit rough and the pain relief wasn’t great but after the first 24 hours it wasn’t bad. My surgeon told me that the surgery had ‘been difficult’ and that he was concerned that my voice may have been affected, but at this stage it was fine. I went home the following day and we began the longest wait of all to find out the pathology results.

Kate is the Founder of the Butterfly Thyroid Cancer Trust. It was after attending a fund-raising function organised by Kate that Living North decided to try and help charities in their work by raising the profile of those lesser known but extremely important organisations through our Changing Lives page. The aim: to encourage readers to become involved.

Kate travels extensively in her desire to raise the profile of Butterfly and is invited to speak at conferences worldwide where she uses her experience of the condition to help others cope with their own crisis. Her roots, however, remain firmly in the North East and Kate also works at the Northern Centre for Cancer Care at the Freeman Hospital, in an unpaid role as Patient Thyroid Cancer Advisor, the only patient to do so, helping others as they begin their journey through treatment and cancer care, offering practical advice and support as someone who has herself undergone the treatment, giving a huge psychological boost. No other cancer clinic in the UK offers this service to patients and it is testament to the forward thinking of the management and doctors at the Trust that Kate can carry out this role.

KATE’S STORY

I am writing in September of 2009, nine years since I was diagnosed with Thyroid Cancer. Looking back so much has happened since then, lots of it has been very positive, but at the time my family and I were devastated at my diagnosis. It was a very busy time in my life. I was working with my husband in his very busy Dental Practice, our son was twelve years old and would soon be preparing for important exams at school and my dad was chronically ill.

I got up one morning and one side of my neck was slightly distended, there was no obvious lump, it felt soft and spongy. I wasn’t in the least bit concerned about what it was because I couldn’t feel a lump, I was blasé about it, it would be nothing. Had I found a breast lump I would have burned rubber on my tyres in getting to see my GP.
It has taken a lot of hard work and determination to succeed but was seven years ago and much had happened since then, all good! was the first person I knew who was going through what I had. That was the beginning of 'Butterfly' which I was involved, visited her in hospital and went with her to scan diagnosis, we talked, lots. I told her about the treatment and what I was worried when I discovered an enlarged lymph node in my neck a few months after this but this was removed and was benign.

A year after surgery I was well on the way to getting my life back on track, we were having a new house built and life was busy. I was back at work part time and feeling that maybe life could 'get back to normal'. Having been a nurse and having had a cancer diagnosis I was fairly 'body aware' and went to see a dermatologist as I had noticed that a tiny mole on the side of my foot seemed to be changing slightly. I wasn’t particularly concerned but he suggested removing it as I thought it had changed. Thoughts of ‘once bitten twice shy’ and ‘no one could be that unlucky could they?’ came to mind when I went to get my stitches removed on the way to work. I had a malignant melanoma, I couldn’t believe it. Again I was told I was lucky, it was in situ, in the earliest stage, and hadn’t spread.

Two weeks after moving house I had a skin graft to remove a strip of skin under my left arm which was sewn onto my left foot to cover where the melanoma had been. I couldn’t walk properly or drive for six weeks. I found myself going regularly for two separate oncology follow ups.

As mentioned earlier, I had a wonderful family supporting me and excellent doctors, I plagued my surgeon and oncologist with endless questions about the disease and my prognosis, they were exceptionally patient with me and did their utmost to support me. I was very anxious and depressed during the initial six months, the only way I could cope was to find out everything I could about my disease and I learned fairly quickly that this needed to be sourced only from my professional medical team and not the internet!

I was lucky, I passed my first six month ‘challenge’ and did not require any further RAI treatment, though withdrawing from Thyroxine and becoming hypothyroid again was a total pain, and the disconnection to both normal family and working life is hard to accept. I was troubled by this and realised through my own experiences that if patients were well informed with reliable information right from the start of their diagnosis and I learned fairly quickly that this needed to be sourced only from my professional medical team and not the internet!

I was very lucky to have the support of a wonderful family and excellent doctors, I plagued my surgeon and oncologist with endless questions about the disease and my prognosis, they were exceptionally patient with me and did their utmost to support me. I was very anxious and depressed during the initial six months, the only way I could cope was to find out everything I could about my disease and I learned fairly quickly that this needed to be sourced only from my professional medical team and not the internet!

A very special thank you must go to a nurse who will forever be a legend to me, that nurse was none other than the wonderful Sarah. I was worried when I discovered an enlarged lymph node in my neck a few months after this but this was removed and was benign.

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As mentioned earlier, I had a wonderful family supporting me and excellent doctors, but I still felt very isolated and lonely at times, no one I knew had even heard of thyroid cancer, radio active iodine, treatment in isolation, challenge scans, or becoming hypothyroid for scans and treatment, let alone experienced it. In Newcastle we don’t have a ‘Specialist or Macmillan Nurse’, and there was no patient support apart from family and during clinic visits. How did people cope who were on their own with this?

I was troubled by this and realised through my own experiences that if patients were well informed with reliable information right from the start and could be given the opportunity to have contact with other patients then it would be beneficial to their wellbeing. I had started to meet with hospital managers and consultants to talk about improving things for thyroid cancer patients and had been invited to talk at a couple of conferences when my surgeon called me and asked if I would talk with a young newly diagnosed patient who was struggling. That really, was the beginning of ‘Butterfly Thyroid Cancer Trust’.

Katherine was in her 20s and understandably devastated by her diagnosis, we talked, lots. I told her about the treatment and what was involved, visited her in hospital and went with her to scan appointments. Not only did this help Katherine but it helped me, she was the first person I knew who was going through what I had. That was seven years ago and much had happened since then, all good! After Katherine, more patients got in touch. I gave up work at the Dental Practice to concentrate on setting up ‘Butterfly’ full time. It has taken a lot of hard work and determination to succeed but the reward in seeing what good support can do for other patients is wonderful. We are now the first registered charity in the UK dedicated to the support of people affected by Thyroid Cancer and are both recognised by and have the full support of the health care professionals treating patients in our region.

Butterfly is a quadruple award-winning charity: Pfizer Excellence in Oncology Award 2006 NHS Innovations Ward 2006. Hospital Doctors of the Year Award (Oncology) 2007 and Pfizer Excellence in Oncology Award (Commended) 2009. What we can offer is detailed in the website www.butterfly.org.uk but to a newly diagnosed patient the opportunity to meet someone who has had the same disease as them and is well/cured so many years on is priceless. No one diagnosed with this rare cancer in the UK needs to go through their cancer journey feeling alone or isolated. Butterfly can offer support, information and encouragement whenever needed.

I am now nine years on from diagnosis and am told I am cured of my disease although I will continue to have yearly follow ups for the rest of my life. After six years of taking calcium supplements I was finally able to wean myself off Alphacalcidol and was given the all-clear from my melanoma two years ago. Nine years of great change and acceptance. Physically I do not feel the same as I did before all of this happened. I cannot do as much without getting very tired and this frustrates me but I am learning to accept that this is just how it is. I am now facing a new challenge in that my Mum has been diagnosed with dementia and I am learning about how to deal with something else that is entirely unknown to me. My experiences with cancer have taught me to enjoy life to the full and that life is about today, not next year or the year after. At the grand old age of 52 I find myself more productive and fulfilled personally than I have ever been!