Paul's Cancer Story

Hello. My name is Paul - I'm from Leeds and I'm a qualified gas engineer and a supervisor for a local authority. My cancer journey started in January 2015.

In January 2015 I noticed a large lump on the side of my neck. This wasn't painful in any way but due to the size I sought medical advice, where the doctor advised me I had tonsillitis and prescribed me with antibiotics. The lump seemed to go down externally but not on the inside of my throat, so I returned to the doctors several times and they prescribed a further 5 courses of antibiotics. I was never in pain it was just difficult to swallow sometimes.

On the 6th visit I saw a nurse as the doctor wasn't available and explained the lump internally wasn't going down and my wife had complained about my bad breath which I didn't normally have. The nurse carried out some observations and took my temperature, and she wasn't happy with the previous diagnosis and said I had to go immediately to the ENT at our local hospital. I was shocked as I was just expecting some pills and all would be ok, but I did as I was asked and went straight to hospital.

On arrival I waited and saw a doctor who examined me and said she couldn't see anything wrong. By this time I was frustrated with the time the illness had been going on, so I refused to leave until I had a second opinion. The doctor arranged a second opinion within 5 minutes and I entered a room with a senior consultant and 2 junior doctors. The consultant looked in my throat and advised she wanted to stick a finger down to feel the mass. This wasn't pleasant at all but she looked at me and said that tonsil will need to come out and be tested; "I think it may be cancer," she said. I phoned my wife who said they are just saying that to cover the worst case and I waited for my surgery appointment.

On the 1st of April (April fools day), I arrived at hospital for the tonsil to be removed. I was nervous, as I had never had an operation before. I went into surgery and when I woke the doctor was waiting for me. He advised the operation had gone ok and once I ate I could be discharged. However he looked at me and said I can't be sure but I'm nearly positive it was a cancerous growth so we will test it and be in touch, so I went home hoping for the best

A few weeks passed and I had recovered from the operation. I received a letter to see a consultant at our cancer hospital, Bexley. At this point I thought it would just be a follow up. I spoke with a consultant who talked about my operation and said they were still waiting for the results but want me to have an MRI in the meantime. At this point I was still relaxed about the situation as I didn't feel poorly. I had the scan and was advised that I would be called back to discuss the results in a few weeks.

> **"That day I will never forget the wife said it will just be a formality but when I walked in the office I was greeted by about 10 people. I knew at this point something was a miss."**

I was advised the tonsil was cancerous t2, n2c carcinoma and I would require Radiotherapy and chemo as it was quite aggressive, and I would need further scans to identify the treatment regime. It all didn't seem real and I still thought it was overkill. Another MRI scan, then CT scan and a pet scan followed, then I was sent for a neck biopsy. A few weeks later I had a follow up appointment and was told I also had a

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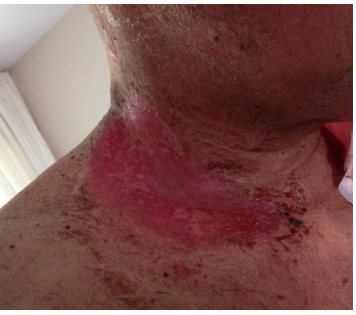
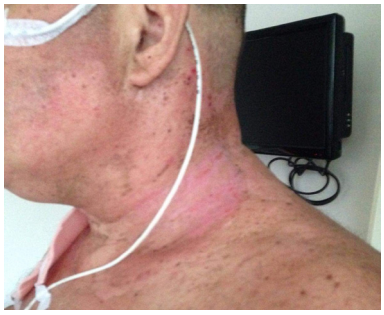
secondary thyroid cancer. This wasn't life threatening and they would deal with it after my treatments.

The treatment plan was to be 3 cycles of chemo cisplatin and 7 weeks of daily radiotherapy ,they did explain all about the side effects and the support but it wasn't sinking in i was in shock but i agreed they needed to do what was required,the one thing that stuck with me was how the cisplatin can cause really bad tinnitus and i needed to let them know I was shown round the department i was fitted for a mask and talked through the treatment it still seemed unreal ,i suggested that i don't tell my children what's happening but staff advised me that neck cancer is the most aggressive treatment and i wouldn't be able to hide it.





I started my first treatment, which was a chemo infusion and radiotherapy on the same day. I remember thinking, "this is nothing," and laughed with the other patients. The infusion took 8 hours - what a mistake! I came home and was so ill, and got up the next day like a zombie. More radiotherapy followed which only took 20 minutes, and I couldn't wait to get home to bed. I remember going for my 4th radiotherapy treatment, still feeling rough and asking a nurse if it was normal to feel this way. She gave me a hug and said, "that's chemo, son."

The regime carried on every day; radiotherapy then home for a nap. The chemo affects had worn off but I had tinnitus, so the consultant advised I couldn't have any more cisplatin as I would risk losing my hearing. I continued with the radiotherapy daily for a further 4 weeks, which wasn't too bad apart from the tiredness. I was struggling to eat and was losing lots of weight. I had another chemo infusion which only took 2 hours and I thought this might not be as bad - BIG mistake - I was just as ill.

I carried on with the treatment and on the 5th week of treatment I had to have a feeding tube fitted as I couldn't eat or drink. I was also prescribed a big bag of medication including morphine, and at the back of my mind I kept remembering how they said if I lost too much weight the mask wouldn't fit and treatment may have to stop. But the weight kept falling off and I eventually lost 4 stone. I remember going for treatment with other cancer patients wondering why I was in a state and they where laughing and joking. That's because cancer treatment to the neck causes the most devastation. The biggest surprise was having to sort out your own feeding tube including cleaning all after a quick training session. I expected a district nurse to help, and the equipment kept failing and I had to ring up for a technician.

I completed one more chemo and the 7 weeks of radiotherapy. I was very weak and the feeding tube was getting me down (depressed). On the day of the last chemo I was so exhausted, that I came home to bed on the Friday and didn't feed myself. My wife made me get out of bed on Monday and said, "If you don't go to hospital I will call an ambulance." A good call because when I got there they advised I was shutting down and gave me fluids and food through the tube .The tube used to come out on a night and I had to go back regularly for a new tube fitting which wasn't pleasant. The medication made me constantly constipated. After 3 weeks of the tube I was clinically depressed and sat with my speech therapist and forced a baby custard down, which took 30 minutes. I was also given the high-energy drinks. She advised that if I worked at that they would remove the tube two weeks later, but I was that down that the consultant removed it the week after and I lived on energy drinks custard and blended chicken soup with cheese.

One side effect I haven't mentioned is the excessive thick mucus. This was relentless and embarrassing but there is no medication available to relieve it. It was a long hard battle but slowly I began to eat again. I worked up from soup, to mashed up meals like a baby with lots of gravy and always water to flush it down as I didn't create saliva.

I was then contacted to have my thyroid removed but was knocked back twice as I wasn't fit enough, and wouldn't survive the operation. Eventually, I was booked in on New Years Eve 2015 for the 2-hour operation and was advised I should be home within 2 days. The operation took 5 hours. When I woke the consultant told me my neck was a mess from the radiotherapy. He told me he hadn't got all the cancer and if he had gone back in he would have had to give me a tracheostomy but I was too young. He also advised that he have removed my parathyroid, as my neck was a mess so my body couldn't produce calcium. I stayed in hospital 3 weeks and they thought I would never speak again due to the damage to my voice box. I had to have daily blood tests every day for 6 weeks until they could stabilize my bloods.

My last treatment was radioactive iodine. This is basically taking a radio active pill and being locked in an isolation room for 4 days, then being isolated from children under 16 for a further 4 days. This sounds easy but when you have been through the ringer it was very hard.

Fast forward and I am now cancer free. I see my tonsil cancer consultant in 6 months then he will discharge me as it has been 5 years, but I will still see my thyroid consultant and endocrinologist annually forever. The side effects keep coming, and the anxiety is a killer.

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