Anthea's Story

Talking about her Melanoma journey, the journey that no one ever wants to be part of, and also the journey that no matter how hard one tries, one can never get off.

"Buckle up people, it's a long and bumpy ride."

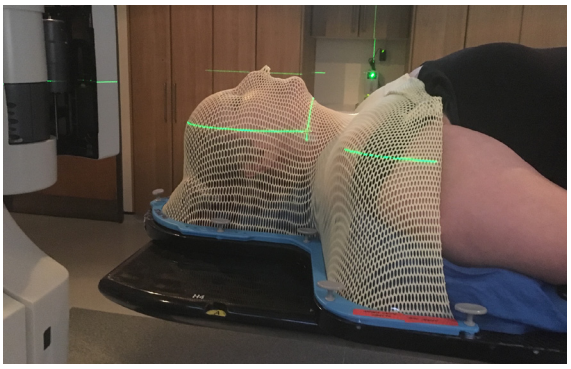
I first noticed a small skin coloured lump on the top of my left ear back in 2010. This small lump used to itch a lot and was noted by my hairdresser a number of times.

I worked for a national children's charity as a counsellor at the time, and also noted that the headset that I wore on shift, also caused the lump to itch and it was felt that I was possibly allergic to the material on the headset. I spoke to my GP about this in April 2010 and was told that it was a wart, nothing at all to worry about and to maybe try over the counter wart treatments if I wanted to.

The lump (or wart that I then believed it to be) continued to itch and grew. I always then wore my hair longer on that side, to hide this, as I was embarrassed to have a wart. I changed jobs and began to work on a national child protection help line, again the issue with the headset continued. I again spoke to my Dr who again continued to say that it was nothing at all to worry about. During an apt with practice nurse, who noted the lesion on my left leg, I explained that Dr was not concerned about both, the Practice Nurse was concerned and booked an apt there and then to see the Dr the following morning.

The Dr reluctantly referred me to Dermatology (non urgently). Fast forward 5 months the Dermatologist focuses solely on the lesion on my leg, stating that the lesion on my ear is simply a wart and that he will treat this at another apt. Follow up apt arranged for 6 months later, I made contact with the medical secretary to request to bring the apt forwards, as the lump on my ear is now growing rapidly and is also bleeding. Follow up apt, I'm told that the Dermatologist cannot freeze treat the lump, as they feared it would cause scarring. I am then referred to Plastic Surgery Team as they will be able to treat with minimal scarring. This referral was again non-urgent.

Two months later, at apt with Plastic Surgeon, I'm asked lots of questions regarding history of sun damage, sun



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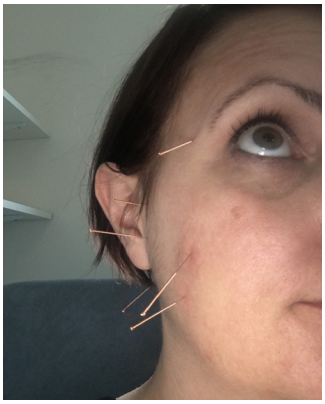
bed use and family cancer history, referred for an urgent biopsy. Biopsy taken, call received from Plastic Surgeons' secretary 10 days later to attend urgent apt for results. Diagnosed with Stage 3c Malignant Melanoma, request for urgent head and neck MRI completed, the following week with contrast. Both myself and my husband walked into the busy hospital at 4pm and walked out at 6pm, in a totally different world, the hospital entrance was still busy, yet we both felt that we were in a different zone, people were moving around us, but we felt as though we were trapped in a bubble. We were advised to speak to our two teenage sons and to write down any questions that we had. Head and neck MRI show an enlarged lymph node on brain stem/spinal column to be closely monitored.

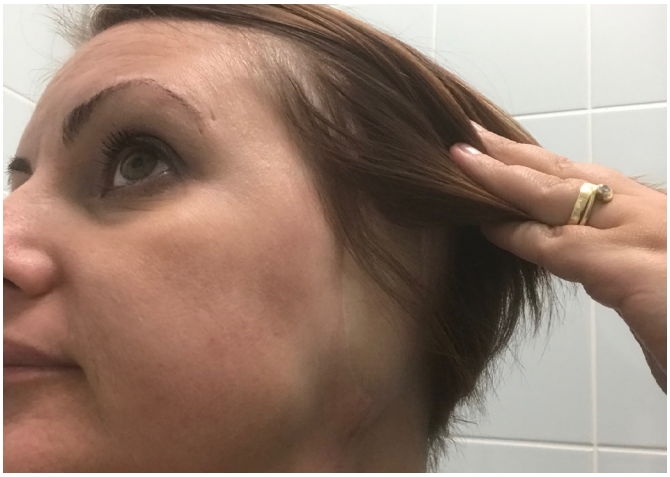
My details are referred to an ENT Plastic Surgeon Consultant, who informs me that the option of surgically removing the tip of my ear, is not an option, and that my whole left ear will be amputated including tragus. I'm advised that this will not impact my hearing, and that if at 5 year survival point I am still alive, I will be able to have reconstruction surgery whereby, bone from rib area is surgically removed, and an ear is surgically grown over two years on my forearm, my head is again spinning. Within this time, I left my long-term post with National Children's Charity and began a new job in the February as I was diagnosed in the July 2015.

"I had my whole left ear amputated and tragus amputated in August 2015. I was informed at follow up apt that sadly healthy margins were not able to be achieved, and that they were referring me for radiotherapy."

One of my Cancer Nurses during a MDT meeting asked the ENT surgeon to also consider further surgical option. It was then that I was referred to another hospital to see a Skull Base Surgeon who had considered the case and options and was under the impression that I had already been advised of the recommended procedure.

So here I am sat in an apt alongside my husband – suddenly being told that the whole left side – inner ear & middle ear will be surgically removed, alongside temporal bone, all lymph nodes on left side, facial nerve to be cut and stripped, all salivary glands to also be removed on left side and skin taken from thigh – to replace using a free flap. Then to be followed up by radical



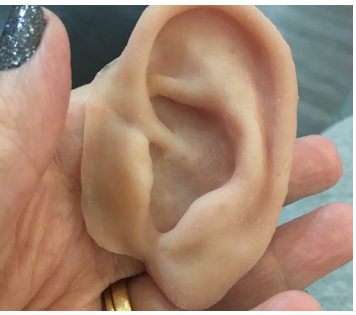


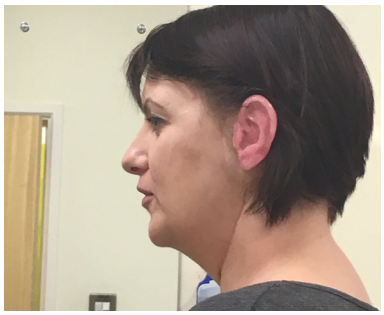
radiotherapy. I would lose all hearing on left side, sense of taste, loss of sensation, as whole left side vestibular system would be removed, there would be major issues with balance and being able to triangulate sound. We were both in shock and were taken to a room to speak to the cancer nurse, again the world had continued to spin, but we were somehow not spinning in line with the rest of the world.

The second surgery was completed in November 2015, 13-hour surgery, I woke up and could hear constant screaming on my left side – Tinnitus that is there permanently. I was told that I would be in hospital for at least a fortnight, I managed to do all that I could to get walking, to get home to be where I could be most comfortable and to be with my husband and sons, I was home exactly a week to the day of my surgery, even with a diagnosis of pneumonia due to being in lengthy surgery.

At follow up apt, the pathology report confirmed that Melanoma was present in areas that couldn't be seen by the naked eye and that had not shown on PET scan, CT scan and MRI scan. This was noted to be a skip metastasis. Decision made for radical radiotherapy to be completed in Jan 2016 – 32 sessions on head, neck and shoulder area.

I totally underestimated how brutal radiotherapy was likely to be, it kicked me and kicked me hard, after session 1 my mouth ulcerated, and this made eating extremely difficult, it also wiped out my sense of taste in whole mouth, as it was already wiped out on left side. The 100 mile round trip each day, Monday to Friday was exhausting and without my husband and wonderful friends I don't think I could have coped with this.





Each session was ticked off, a step closer to banishing this beast. I received a lot of medication to help soothe the sores in my mouth, aqueous cream to apply to soothe skin damage and burns from the radiotherapy. I received ensure plus drinks to assist with nutrition. I had sessions with speech and language therapy team, and dietician as these were concerns. On the last session, I rang that bell three times to mark the end of treatment, I also brought my mask home with me, that was moulded around my head and shoulders and was clipped on top of me onto the bed each day.

"On a lighter, humorous note, I cope by seeing humour in stressful situations. When session one of radiotherapy was commencing, I was clipped to a bed and couldn't move, whilst the music playing was their choice... cue the first song: Lightning Bolt by Jake Bugg, just as the beam is zooming close to my face! It really did put a smile on my face."

I then went onto six weekly checks with skull base surgeon, six weekly checks with oncologist, I requested to be seen by a different dermatologist to receive ongoing mole mapping, these appointments are three monthly. I have had a number of lesions removed and thankfully they have been benign. I asked to receive six monthly scans to monitor, I have been receiving six monthly head MRI scans and also six-monthly CT scans on Chest, Abdo and Pelvis, both with contrast. I am now also under the care of a Tinnitus consultant, to look at coping strategies for my permanent Tinnitus, a Maxillofacial consultant as I have trismus following radiotherapy that causes headaches, jaw pain and a tense jaw, I have facial physiotherapy to treat this issue and have to sleep with a mouth guard to prevent jaw clenching in my sleep and a device to maintain the opening of my jaw that I use daily. I still have issues with loss of sense of taste on my left side, including numbness and I have a prosthetic ear that I apply using a skin friendly glue.

"I have been advised that at the five year survival mark, I could consider reconstructive surgeries, at this point I do not feel that I want to undergo further surgeries, unless they are to preserve life. But yet, here I am still alive, so all of the above side effects are a small price to pay, for still being able to be a wife, a mother, a sister, a daughter in law, a sister in law, an aunt, a cousin, a good friend and ME."

I returned to work in May 2016 and continue to work full time, work helps me as work is my normal, I am able to help others. I do struggle at times and often feel overwhelmed, I have accessed counselling and am now awaiting an apt with a psychologist. As I find it hard to accept the uncertainty that melanoma brings. I'm told to forget about it and to live life, I've also been told all the way through from diagnosis, how sneaky and how aggressive my melanoma is, that now its hard to change that, but here I am at the three year mark.

I did have many sunburns as a child, I also did use sunbeds, I loved having a tan, it made me feel better about myself and made me feel more confident. If I could change one thing, it would be to erase all of that, but sadly I can't, but what I can do, is to educate others, and to try to also raise awareness on the dangers of sun bed use and sun damage/sunburn.

If I can help, just one person, to prevent them from all of this, then I have made a difference. I am not perfect, I continue to feel overwhelmed at times but each day I also continue to be the best that I can be.

Thank you.
Take very good care of yourself.

Anthea

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