

www.melanomarollercoaster.co.uk



On Tuesday 11th June 2013 I was informed I had Malignant Melanoma.

Understandably I was surprised, shocked and very scared. I had no idea what MM was or how it would change my life.

The WLE was done on the same day I was diagnosed & I left hospital that afternoon with a 7 ½ inch scar down my back and a Macmillan leaflet on skin cancer.

From that point onwards I have fought for my health almost every step of the way.

I was offered a CT scan 6 weeks after my surgery – I thought that was too long a wait so asked if I should get one done privately & was advised that if I could it was a good idea. After pushing various departments I was offered an evening cancellation 1 week later.

I was informed by the nurse that I was very unlucky, my Melanoma was ulcerated, 4.7mm deep and I had a mitotic rate of exceeding 10/1. Thankfully the CT scan was clear. Stage 2C.

I was told I was unlikely to see an oncologist – I pushed – the oncologist advised me that there were no options for me on the NHS. No SLNB, no tests, no drugs because there was no money in the Cancer Drug Fund. I asked about clinical trials & was advised that to get onto one I would need an SLNB – which I would need to pay for privately.

I pushed to meet with the trial team in Oxford before I committed to the cost of a private SLNB. I met with the team in Oxford & was advised that there was no need to pay privately for the SLNB and this could be undertaken there as part of getting into the clinical trial.

Everything with Melanoma was happening so fast I was spending hours every evening on the phone to family members updating them individually about the latest developments.

I was on the internet researching Melanoma & my options all the time – I had found many blogs from America but none from UK Patients. It was at this point I decided to write my blog.

I have a background in IT and followed a YouTube tutorial on creating your own blog through Wordpress. I found it quite cathartic. I had been keeping a journal so it was easy transferring my experiences and frustrations into posts.

I have 2 young children (they were 5 and 6 at the time of diagnosis). We hadn't & still haven't told them about Melanoma. I wanted the blog to be a record for them – of what I had gone through – so that many years down the line when they are old enough to process melanoma & cancer and how it has impacted on our family they could read the blog and understand.

www.melanomarollercoaster.co.uk was created.

I own my own domain, utilise a mailing program to send email notifications to subscribers when the blog is updated and have my blog linked to specific accounts and pages on both Facebook & Twitter.

The Blog has grown. Not just in terms of size from frequency of posts & updates, but in terms of its audience & remit.

Through the blog I get approached and contacted weekly by patients with similar experiences.

I have been contacted by the media & have shared my story in the national press.

I have worked with The British Skin Foundation to create & launch a dedicated Skin Cancer charity called ItTakes7.

I have joined a EUPATI network of patient advocates & have attended several conferences and events with them in Europe to unify and improve patient care & information sharing across countries.

I am dedicated to raising awareness about Melanoma & helping ensure that communication systems improve so that no other patients experience the issues that I did. My specific focus is upon improving long term survival of cancer patients – specifically through lifestyle & nutrition.

I use social media as a tool; through social media I have a far wider reach. I liaise with governing bodies, charities and researchers across the world and share data that is of interest and holds important note.

Social media – especially Twitter is responsive – to use it you must be active – frequently. People expect quick responses and almost instantaneous interaction. There are specific social media “etiquettes” to learn and absorb.

I never tweet or post on Facebook something I am not prepared to discuss & justify. Opinions are allowed (and encouraged) but slander and sweeping statements opens people up to criticism & Twitter is a minefield.

I post a blog to the website almost every 2 weeks but engage in conversations on both the blog's Facebook page & Twitter in between blog updates. Each update is read by an average of 2,500 people although several readers catch up on the blog every couple of months and then read several pages at a time.

I welcome and encourage new subscribers and email communication.

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