

Eleanor's story

Some readers may recognise me from a few previous articles I've written for this wonderful little guide, as a technology blogger.

This feature however is a bit closer to the heart and ironically, technology, although indirectly may be helping from a medical perspective, is not going to take this awful situation away in a hurry.

I refer to my daughter Eleanor who is only 4 years old and has now been diagnosed with an inoperable brain tumour. Unfortunately it is in such an awkward location that she has now lost her eye sight too.

My own experiences with cancer have taught me to try not leave anything to chance where health is concerned so fortunately my fiancée and I acted relatively quickly with regard to Eleanor's diagnosis and pushed hard for tests.

Towards the end of 2014 we noticed a marked decline in Eleanor's visual abilities, she started to draw things in closer to her face, lost interest in the TV and meal times became difficult, when before they were easy. At first we put the majority of it down to age and the fact that she would probably just need glasses. It soon became apparent though that her eye sight was suffering so much that she could hardly see something she had dropped right at her feet. We would get frustrated, as I'm sure most parents often do, that she would not pick a toy up when told, but in hindsight we now know she could barely see it to pick it up!



"Tim Stollery of maxximium is a self employed computer consultant who has been providing support, training and advice for users of Apple Computer equipment for over 25 years, from small to large installations. He's an independent Apple 'genius' available to provide you with regular support, advice and/or training in your home or at your business premises."



Come early November 2014 we visited a high street optometrist to get Eleanor's eyes tested, she played up a little so could not be properly checked. The optometrist suggested visiting her GP to get her eyes properly looked at, and although was unable to check in great detail pointed out that her eye sight was not good and wrote a letter of referral for us. We went again to another optometrist for a second opinion mid December where Eleanor was much more co-operative, then on the 30th December visited her GP for the referral. Chasing the referral a day later at Kingston Hospital and again on the 2nd January revealed that they would not prioritise Eleanor's case, despite our concerns. So we decided on the 5th January, when all the top consultants would be back from their holidays to take Eleanor to Moorfields Eye Hospital in EC1, where they have a paediatric walk in clinic. In hindsight with Christmas and the New Year in the way we really

acted as quickly as we could have been expected to with what we initially considered as just a vision / glasses related problem.

The 5th of January 2015 was to be the start of something extremely challenging for us all to deal with.

After several specialists at Moorfields checked Eleanor's eyes they agreed something was wrong with her optic nerves, a blockage, so she would need an urgent MRI scan to determine the cause. On the 8th January at St George's Hospital, under general anaesthetic, Eleanor was given that MRI, and the news was given to us there and then that they had found a large tumour present in the hypothalamus region of her brain, over her optic nerves, just about where they cross over. A week later on the 15th January, Eleanor was admitted to The Royal Marsden in Sutton for urgent surgery to fit a small port on her body to make treatments and tests easier. The very next day, chemotherapy was started.



Those of you that have had experiences with cancer will know the roller coaster that has since ensued.

It turns out there is nothing wrong with Eleanor's eyes, it's the tumour stopping the messages from getting through to her brain. If you like, it's similar to someone stepping on a hose pipe, the tap is fine, the hose pipe gun functioning perfectly, but there is a blockage along the way. Unfortunately taking your foot off of the hose

pipe, in this instance, is not going to solve the problem. Optic nerve damage within current medical knowledge is irreparable. With the eye sight issue aside, this is not the main problem we are dealing with here either, there is still the matter of getting this tumour to shrink to a manageable size so it does no further damage and that is no mean feat in itself, brain tumours are notoriously hard to treat as the human brain protects itself pretty well from any form of foreign chemicals reaching it, something called the blood brain barrier which I'm sure some of you may have heard mention of.

As I'm sure you can appreciate it has taken me until now to bring myself to write about this in too much detail but not long after this all started my fiancée Kelly and I decided to start an awareness campaign, highlighting the importance of getting things checked at the earliest opportunity.

Had we even remotely suspected that our otherwise perfectly healthy daughter had a brain tumour and looked to the biggest children's brain tumour charity in the UK for guidance (HeadSmart), they don't even list vision problems such as this in their under 5 category, so not even health practitioners, GP's and the like would even remotely consider a brain tumour being the cause of such problems. What they do list are symptoms that you would expect should you be a lot further down the line with tumour size or severity.



We have since requested that the symptoms listed for the under 5's be changed, but the response was not very welcoming, so to that end we will raise as much awareness as we can, alone, until it is changed!

How you can help us...

Eleanor's story is shared via Twitter and Facebook and we need to get her message out as far and wide as possible. Liking her page on Facebook and sharing individual posts helps raise awareness in itself. Following her on Twitter and tweeting about her to your followers in turn getting them to follow her story will expedite the message. Ultimately by sharing her message and raising awareness we might just save another child's life by getting checks and/or treatment started quickly.



Eleanor also has her own website at www.eleanorstollery.com and her Mum Kelly, has her own blog which intricately details much more about Eleanor's story, particularly from a mother's perspective at www.tangledhope.com

The twitter account for Eleanor is @erstollery and this is mirrored on her Facebook page by searching for 'Eleanor's Voice' on Facebook or simply '#eleanorsvoice' in Google!

I have my own cancer awareness website (timstollery.com) which I have run for many years, so it is a matter close to my heart to help others and raise awareness. The cancer that I suffered is unrelated and in recent tests, along with a meeting with a geneticist, revealed just how unlikely that is in our current understanding of genetics.

Eleanor cannot see much at all any more, so when we can we get her to carry her 'symbol' cane, this is a white cane which symbolises the fact that she cannot see very well at all. So if you ever see a little child carrying a white cane, be sure to step aside and let them pass, don't expect them to see you to get out of the way. In time Eleanor will use her own 'long' cane or mobility cane to get around herself.

This guide as well as other publications are fully behind us and supporting us so please get behind us too, and if you see Eleanor in and around Hampton please feel free to say "Hello!". I'm certain this will not be the last you hear of this story either!

Thank you in advance for your support.