

# Eleanor's Story, one year on...

I've written for this wonderful little guide before, as a technology advisor. This however is a bit closer to the heart, and is an update to the article I wrote in the September 2015 issue of the Hampton Guide.

I refer to my daughter Eleanor who is nearly 5 years old and has been undergoing chemotherapy for just over a year since she was diagnosed with a rare and inoperable brain tumour (hypothalamic glioma).

Unfortunately the tumour is in such an awkward location that she has now lost her eye sight too.

Up to the age of almost 4, Eleanor was happy, confident, and to all intense purposes, a completely healthy and thriving little girl. Towards the end of 2014 we noticed a marked decline in her 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. Although it soon became apparent that her eye sight was suffering so much that she could barely see something she'd dropped right at her feet. After pushing hard for tests, the 5th of January 2015 was to be the start of something extremely challenging for us all to deal with.

Over this past year she has undergone a minor operation to have a 'portacath' fitted (a medical device enabling her to be treated more easily), harsh chemotherapy, multiple lengthy MRI scans under general anaesthetic, countless blood tests at hospital, home and at school, a blood transfusion, hearing tests, kidney function tests, hormone tests, spikes in temperature, allergic reactions, hair loss... the list goes on! That's just the medical element, which continues at such a pace it's hard to keep up! Additionally and along with the amazing support of Richmond Council's Achieving for Children, Eleanor has also started in a main stream school, is learning to walk with her 'long' cane, learning braille and generally learning to live with her disability. She still manages to smile through it all! How resilient our children can be, even at the worst of times. I may well be be biased but to say she is inspirational is an understatement!



At the very beginnings of this horrible journey, my fiancée Kelly and I decided to start an awareness campaign, highlighting the importance of getting health concerns checked at the earliest opportunity. Although we realise that we may not be able to save the world, we can surely make a difference and if nobody at least tried, nothing would ever change for the better!

"Tim Stollery of maximum is a self employed computer consultant who has been providing support, training and advice for users of Apple Computer equipment for over 27 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."



We implore you to help us by following and sharing Eleanor's story, our story, through your own social media channels. It could just save another child out there or convince another parent to finally push for important tests their child might need, or at the very least, allay their concerns. Our awareness campaign has steadily been gaining momentum, so it's now fairly easy to find. Simply search for the hashtag #EleanorsVoice on any platform you may use, ie. Google, Facebook, Twitter etc. Give it a try!

On reflection, if we'd have even remotely suspected that our otherwise perfectly healthy daughter had a brain tumour, and had looked to the biggest children's brain tumour charity in the UK for guidance, namely HeadSmart, they don't even list vision problems such as this in their under 5 category! With this in mind, not even health practitioners, GP's and the like would even remotely consider a brain tumour being the cause of such vision problems. What HeadSmart do list are symptoms that you would expect to experience 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, perhaps by simply adding "rapid vision changes" to the list, but our requests have so far been ignored. To that end, with your help, we will attempt to raise as much awareness as we can, until it is changed!

What's in store for Eleanor... At this stage her chemotherapy treatment continues, either until the end of the current course or until she exhibits just too much toxicity from the harsh drugs chemotherapy is made up from. So far, in a year there has been no change in the size of her tumour. Looking at the positives it hasn't gotten bigger but then on the flip side it hasn't gotten any smaller. Hopefully the treatment she's endured thus far, has kept it stable. After this chemotherapy we will be on what's known as 'watch & wait' and during this time she will be regularly monitored using MRI scans. These are lengthy and require her to be very still for about 45 minutes. This is a challenge for any 4 nearly 5 year old! Eleanor has to be put to sleep, which is never pleasant to watch. If the tumour gets bigger, she goes back on another different course of chemotherapy. Once she reaches an age where her brain is considered mature enough -about 8- she will have to have Proton Beam Therapy, which by that time will hopefully



be available on the NHS in several locations around the UK, if not, we will be sent abroad, most likely to the USA. Proton Beam Therapy presents its own risks, despite the wonder stories the main stream media choose to print. Besides, this type of treatment just hasn't been around long enough to prove its overall effectiveness or what the long term implications or side effects could be.

Family, friends and the local community still continue to amaze us with their generosity and kindness. It's so hard to thank each and every one of you, but we are eternally grateful for your support. Even the local Conservative MP, Dr Tania Mathias has offered a helping hand, as not only is Eleanor in her constituency but her case is of particular interest to Dr Mathias's field of medical expertise too.

We are of course grateful to The Hampton Guide who continue to follow Eleanor's journey and we will keep you up to date with her progress in the next issue of the guide.

Thank you to all for continuing to support #EleanorsVoice

