

# Eleanor's Story... Watch & Wait Scanzxiety!

You may have read about our daughter before in previous editions of this wonderful local guide.

Eleanor is almost 6 years old, and since Jan 2015 has undergone extensive chemotherapy for a rare and inoperable brain tumour, known as a hypothalamic glioma or pilocytic astrocytoma.

Unfortunately the brain tumour is in such a difficult location that her eyesight has all but been lost too.

Up to the age of almost 4, Eleanor was a happy, confident, and to all intents and purposes completely healthy and thriving little girl. Towards the end of 2014 we noticed her vision changing; 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 that her eye sight was suffering so much that she could barely see something she'd dropped right at her feet. After pushing the NHS hard for tests over the 2014 Christmas holidays, the 5th of January 2015 was to be the start of something extremely challenging for our family to deal with. Eleanor's brain tumour diagnosis, our lives were literally turned upside down.

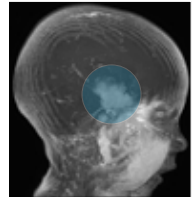
Bringing things up to date; Eleanor has now finished the first line of treatment for this type of brain tumour; a gruelling 18 months of chemotherapy to which she has coped with admirably. Not only has this tumour taken her eyesight it has also caused some damage to her pituitary gland (the hormone centre). This was beginning to present itself via various tests Eleanor has had to undergo, and if left untreated would cause her to enter in to puberty, way before it should happen naturally. So now if the

chemotherapy wasn't enough, she has to undergo a nasty intramuscular injection, every four weeks, until she is 11 years old! We hope she'll eventually get used to having them but so far after three injections, we are no closer to them becoming any easier.

Next up is an MRI (by the time you are reading this article we should know the results). The lead up to these regular 'monitoring' or watch & wait scans is a very anxious time for us. We know the brain tumour is still there, it's not going away and we can only hope it might be getting smaller or staying stable.

Watch & wait is a horrible phase to be in, if the tumour grows Eleanor goes back on chemotherapy, if it stays stable we wait for the next MRI scan (every 3 to 4 months). Sometimes the anxiety is overwhelming, and is more commonly known as "Scanzxiety"!

"Tim Stollery of macximum is a self employed computer consultant who has been providing support, training and advice for users of Apple Computer equipment for over 28 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."



Finally, once Eleanor reaches an age where her brain is considered mature enough -about 8- she will most likely have to have Proton Beam Therapy, which by that time will hopefully be available on the NHS in the UK, if not, we will probably be sent abroad, possibly to the USA, but who knows what the future holds! 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.



At the very beginnings of this horrible journey, my fiancée Kelly and I decided to start an awareness campaign, following our daughter's journey but with an underlying tone aiming at the importance of getting all of our precious children's health concerns checked properly at the earliest opportunity. We called it "Eleanor's Voice".

Through your own social media channels, could you help us by following and sharing Eleanor's story? It could just convince another parent to finally push for important tests their child might need and at the very least, to simply allay their concerns. At the worst, getting someone in to treatment sooner rather than later is by far the better option. Our awareness campaign has steadily been gaining momentum, so it's now fairly easy to find. Simply search for the hash tag #eleanorsvoice on any social media platform you may use, ie. Google, Facebook, Twitter or Instagram. Give it a try!

After some campaigning and complaining, the biggest children's brain tumour charity in the UK, namely HeadSmartUK has decided to finally change their symptom guide to include vision loss in their under 5 category. WE ARE actually starting to make a difference! Hopefully now, health practitioners, GP's and the like might also consider a brain tumour as being a possible cause of any vision problems and refer a patient for immediate tests.

Friends, families of Eleanor's school friends, the local community and businesses continue with their generosity and kindness. It's so hard to thank every one as much as we'd like to, but we are eternally grateful for all your support. The Hampton Guide will continue to follow Eleanor's journey and we will again update you all with Eleanor's progress in the next issue.

Thank you so much to all for continuing to support and follow #eleanorsvoice

An advertisement for Macximum Consultancy &amp; Support Services. The background is a scenic landscape with mountains and a sunset sky. The text is centered and reads: "macximum" in large, stylized, metallic letters. Below it, "CONSULTANCY &amp; SUPPORT SERVICES" in smaller, bold, black letters. Then, "Need help with your Apple Mac, iPhone / iPad, Wireless or Website ?" in bold, black letters. At the bottom, "Apple Computer Specialist" in bold, black letters, followed by "contact@macximum.com" and "www.macximum.com" in a smaller font.