

# Eleanor's Story

## Brave beyond words...

You may have read about our daughter before in previous editions of this wonderful guide, which has followed our story from the beginning... Eleanor is now almost 7 years old, and since January 2015 has undergone extensive chemotherapy for a rare and inoperable cancerous brain tumour, known as a Hypothalamic Glioma or Pilocytic Astrocytoma. Unfortunately this brain tumour is in such a difficult location that sadly 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 a 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 had 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, our lives were literally turned upside down.

Fast forward 3 years on and the most recent MRI scans from October 2017 and January 2018 have not only shown very small growth of the large inoperable tumour, but another much smaller tumour has also popped up in a different location in Eleanor's brain. This new lesion, tumour or deposit is currently growing at a rate of about 1mm a month and believe it or not, in our world this is relatively good news, not the best we could've hoped for, but it could be a lot worse!

It does however throw a spanner in the works! Where the main larger tumour was originally classed as 'benign' -which is by no means any reason to breathe a sigh of relief- it is now classified as 'malignant'. This in itself complicates the treatment pathways that are open to us, and we now have some tricky decisions ahead of us in the coming months.



From Eleanor's perspective life carries on, and as she is a little older now it is easier to articulate to her what is going on and what our, or her, options are, but she just gets on with it regardless. Children are very resilient!

At Eleanor's most recent MRI scan in January, she reached a huge milestone. It was her 11th MRI but the first time she'd attempted to do it without a general anaesthetic. These MRI scans require that she lie still for around 45 minutes in order that they can scan her head and spine - a huge feat for any 6 year old in an extremely noisy machine!



When deciding how best to approach this new MRI experience, Eleanor's rationale was not to listen to audio books or music, for fear of laughing at a funny part or wanting to dance, instead she opted for classical music! She breezed through the scan, understanding how important it was to lay absolutely still when asked. It made us so proud, she has certainly had to grow up very quickly in these past few years.

Future MRI scans can now be carried out swiftly and are a lot easier for all of us, especially Eleanor. No need to starve her all day so she's nil by mouth for the anaesthesia and taking the worry away from us of waiting for her to wake and recover from an anaesthetic. Unfortunately the MRI scanner will become a very familiar place to Eleanor throughout her life, and at the moment she has to have an MRI scan about every 3 to 4 months to monitor the tumours.



Eleanor has been enjoying her new found space at home. At the beginning of this journey a group of close friends organised a huge charity ball, raising money so we could make changes to our home to better suit Eleanor's needs, a little like a DIY SOS. Bitter sweet for us but it has begun to make our living environment so much nicer. As with any renovations there have been several obstacles which have caused us problems - local builders not delivering on promises (despite being well paid), false offers of help and local planning restrictions. A lot of which is still ongoing, but we are constantly humbled by those that do go out of their way to genuinely help us in what is a situation we wouldn't wish on our worst enemy. Thankfully the good people are too many to mention and the bad can be counted on one hand. Most recently Eleanor has been learning to play the piano. It comes fairly easy to her from a dexterity perspective as she has already had to learn to use a braille. We are extremely grateful to her teacher for all the time she is dedicating to give Eleanor this opportunity. Who knows where this might lead but any strings we can add to her bow is going to give her better chances in life, given that she has this huge disability in what is a very visual world.

We are constantly humbled by people challenging themselves to raise money for Eleanor. Granting her new opportunities, experiences and buying tools which make Eleanor's everyday life easier, all of which come at a hefty price. Others are raising funds in Eleanor's name, for our chosen charity "Brain Tumour Research", who's scientists we have met and labs we have toured, as they try to get us all #closetoacure.



Thank you so much to all for continuing to support and follow our daughter's journey, and thank you for stopping by to read our article. With the very best wishes for 2018, Tim, Kelly & Eleanor.

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