

Eleanor's Story - #eleanorsvoice

More brain tumour growth, means more chemotherapy for this little girl...

You may have read about our daughter Eleanor before in previous editions of this wonderful guide, which has followed our story since she was diagnosed at barely four years old.

Eleanor is now a very grown up seven year old, some say wise beyond her years. She has already undergone an 18 month regime of extensive chemotherapy for the rare and inoperable cancerous brain tumour she has. Otherwise known as a Hypothalamic Low Grade Glioma or Pilocytic Astrocytoma. Unfortunately this brain tumour is in such an awkward location that sadly her eyesight has all but been lost too.

Fast forward almost three & a half years and the most recent MRI scans from Jan & Apr 2018 have not only shown very small growth of the large inoperable tumour, but another much smaller tumour has 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 news we could've hoped for, but believe us, it could be a lot worse!



Amongst the multitude of tests and appointments that Eleanor often faces, we of course have regular consultations with Eleanor's Oncologist, and in May 2018, the decision was taken to put Eleanor on another regime of chemotherapy -particularly as this smaller tumour continues to grow- as we need to try and stop it in its tracks, or even better, hopefully shrink it, along with the main tumour. If left to chance, this new tumour, along with the main tumour, could begin to do more damage, so we literally have no choice but to try further treatment.

This time the chemotherapy treatment consists of a gruelling 52 weeks of a drug called Vinblastine, administered once a week. This particular chemotherapy requires a blood test approximately 24 to 48 hours before treatment is due, to check that Eleanor is well enough to take either the full dose, a reduced dose or no dose at all (until she recovers enough to take more treatment).

So in mid June, Eleanor has for the second time had surgery to fit a treatment port called a Portacath, and very shortly after that, treatment commenced. A blood test is taken every Monday morning at home before school and if treatment is to go ahead, the chemotherapy is administered in a hospital setting on a Wednesday after school. It has been quite tough to get everything and everyone to fall in to place to make this happen without disrupting Eleanor's schooling too much; community nurses, hospitals etc all need to fall





in to place and everything needs to be carried out on time both with Eleanor and behind the scenes. We hope we have a routine of sorts now and one that will carry us forward through the year of treatment ahead.

We aren't necessarily expecting a smooth road ahead, MRI scans will be taken every 3 months and if after two scans (6 months), there are no signs of progress (tumour stability or shrinkage) then the chemotherapy will be stopped and we will have to pursue other avenues that might be available.

Chemotherapy means Eleanor will often have low immunity and may be prone to infection, so could frequently be admitted to hospital for antibiotic, blood or platelet transfusions during the course of this treatment. If she gets a temperature we cannot just give over the counter medicines, we cannot ignore it, she probably would need to be admitted to hospital.

Some children sail through this treatment, some don't. Some children do really well on it and show good progress against the disease, some don't. It really is an unknown, but then isn't all chemotherapy the unknown?

During the previous regime of chemotherapy it was a real struggle to maintain Eleanor's attendance at school, and to make matters worse at the time, her school was also not very sympathetic to our cause. This time around we are committed to maintaining Eleanor's attendance at school so she doesn't fall behind too much, but at the same time very conscious that her health comes first. Thankfully due to some senior staff changes at her school we are now able to work hand in hand with them, and their understanding of our situation is now second to none! This alone has lifted a huge weight from our shoulders, as we already have enough to be dealing with.

HOME EXTENSION SPECIALISTS

FLUENT ARCHITECTURAL DESIGN SERVICES LTD

- ✿ Free onsite consultation with an experienced designer
- ✿ Quality Architectural & Building Regulation Plans
- ✿ High planning approval rate
- ✿ Simple guided approach
- ✿ Competitively priced

We specialise in helping home owners in and around Surrey, Middlesex, Berkshire and West London to create beautifully designed home extensions, loft conversions and new builds.

CONTACT US TODAY

0800438838

INFO@FLUENT-ADS.CO.UK



LOFT CONVERSIONS - EXTENSIONS - NEW BUILDS

So here's to a year practically stuck at home, of course we can go out but we are quite tied to staying near to home, the community nurses and the local and main hospital where Eleanor is treated. We will try to get away for the odd long weekend but we are increasingly running out of ideas to keep a bright, bubbly but severely visually impaired little girl engaged in what is otherwise a very visual world.

One of Eleanor's biggest loves is Harry Potter, she has listened to both versions of the audio book collections (by Stephen Fry & Jim Dale) and has watched the audio described versions of all of the films, all more times than we care to mention! She has sat through both parts 1 & 2 of the Cursed Child audio described theatrical performances, all in one day, and has also visited The Harry Potter Studio Tour. We just don't think there is anything left to feed her insatiable appetite for all things Harry Potter!



Most recently Eleanor has appeared on the front cover of the Richmond & Twickenham Times, but as it is now old news and with everything else that goes on in the world, 'yesterday's news' is quite quickly forgotten. We are committed to continuing to raise awareness of this horrible condition, amongst others. Ensuring parents, health professionals and medical professionals are aware of the symptoms and act on them. It is imperative that things are checked and checked again until you are completely happy that all has been done to allay your worries.

Moving in the medical circles we now frequent, we have met many parents and children who all have a different story to tell, some tragic. We've lost children we've met, seen them suffer and seen them survive, against the odds. It's a really tough reality that we are now exposed to on a regular basis.

Outside of these circles in 'normal life', Eleanor is very lucky to still have her Great Grandmother, 'Great Nanny' who she absolutely adores. Unfortunately Great Nanny now lives alone in North Finchley, so it is quite hard for us to get there often. Great Nanny's mental and social wellbeing benefits from Eleanor's visits and Eleanor hugely benefits from spending time with her. We are currently trying very unsuccessfully with RHP to get her transferred in to the borough, but waiting lists are long and time is certainly something that is against us.



It seems we are still also at a stalemate with planning approval on our house. Fortunately Eleanor has been granted an accessible ground floor toilet by LBRuT, which we have room to have fitted, but planning conditions stemming from home improvements that our 'ex' builder messed up, all whilst soaking up a huge chunk of funds, are now holding this up and we just don't seem to be getting any straight answers from anywhere. We are desperately in need of some DIY SOS to get things finalised, it would just be nice to have a finished house, and garden, and not to have to think and worry about all of this, we really have enough going on worrying about our daughter.

We are still 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 charities like "Brain Tumour Research" and local charity "Momentum".

Thank you so much to all for continuing to support and follow our daughter's journey, and thank you for again stopping by to read this article. Wishing you good health & happiness, Tim, Kelly & Eleanor.

To follow Eleanor online please visit www.eleanorsvoice.com - or search anywhere for **#eleanorsvoice**