

# Eleanor's Story

## To treat or not to treat...

You may have read about our daughter before in previous editions of this wonderful guide, which has followed our story from the beginning. We are a local family trying to raise much needed awareness around what has happened to our daughter.

Eleanor is now almost 6 and a half years old, and since Jan'15 has undergone extensive chemotherapy for a rare and inoperable 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 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 Jan'15 was to be the start of something extremely challenging for our family to deal with.

Eleanor's brain tumour diagnosis was upon us and our lives were literally turned upside down.

It has now been a year since Eleanor finished the standard first line of chemotherapy treatment for these types of tumour, a gruelling 18 months! Which she coped with admirably. Not only has this tumour taken her eyesight it has also caused some damage to her pituitary gland (the hormone centre).



So if the initial chemotherapy wasn't enough, she now has to undergo a nasty intramuscular injection, every four weeks, until she is 11 years old! She also gets an MRI scan every 3 to 4 months under general anaesthetic to monitor the tumour.

Sadly, the most recent MRI scan has shown some growth, of which Eleanor is blissfully unaware - *that's how we will keep it for now, no point in worrying her, that's what parents are for!* Unless she becomes symptomatic (hopefully unlikely), her next MRI around Sept or Oct, will be an all critical one; it's where the oncology doctors will decide if they are going to treat now or continue to wait. It's simply a toss up between having the toxicity of more chemotherapy (currently our only defence) or the further damage the tumour may cause if left alone.

The next treatment regime of chemotherapy is 'second line' and would last for 52 weeks, given once a week through a medical port, which would again have to be fitted by surgery.



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 call it "Eleanor's Voice". After campaigning and complaining directly, the biggest children's brain tumour awareness charity in the UK, namely HeadSmartUK (aka The Brain Tumour Charity), have finally decided to change their campaign materials both in print and online, specifically to include "vision loss" in their under 5 age category - something that we were keen to highlight, as it was previously overlooked.

**HEAD SMART**  
EARLY DIAGNOSIS OF BRAIN TUMOURS

**symptoms card**

This card is designed to help you know and spot the signs and symptoms of brain tumours in children and teenagers.

Any child or teenager with symptoms that are unusual for him or her, or are persistent or unexplained, should be seen by a GP. If you are worried, make an appointment with your doctor.

Please remember any child or teenager needing urgent medical help should be taken to the nearest emergency department or dial 999.

10 children and teenagers are diagnosed with a brain tumour every week in the UK. That's more than one a day.

Early diagnosis of brain tumours can save lives.

HeadSmart is funded and promoted by The Brain Tumour Charity and run in partnership with the Children's Brain Tumour Research Centre (CBTRC) and the Royal College of Paediatrics and Child Health (RCPCH).

If you would like to talk to someone about brain tumours, please contact the Support & Info Line at The Brain Tumour Charity on:

Freephone  
**0808 800 0004**  
or email  
[support@thebraintumourcharity.org](mailto:support@thebraintumourcharity.org)

[headsmart.org.uk](http://headsmart.org.uk)

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So, with a plentiful social media following **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.

**BABIES**  
UNDER 5 YEARS

- Persistent/recurrent vomiting
- Balance/co-ordination/walking problems
- Abnormal eye movements or suspected loss of vision
- Behaviour change, particularly lethargy
- Fits or seizures (not with a fever)
- Abnormal head position such as wry neck, head tilt or stiff neck
- Increasing head circumference (crossing centiles)

If your child has one of these, see your doctor, if two or more, ask for an 'urgent referral'

**CHILDREN**  
5 - 11 YEARS

- Persistent/recurrent headache
- Persistent/recurrent vomiting
- Balance/co-ordination/walking problems
- Abnormal eye movements
- Blurred or double vision/loss of vision
- Behaviour change
- Fits or seizures
- Abnormal head position such as wry neck, head tilt or stiff neck

If your child has one of these, see your doctor, if two or more, ask for an 'urgent referral'

**TEENS**  
12 - 18 YEARS

- Persistent/recurrent headache
- Persistent/recurrent vomiting
- Balance/co-ordination/walking problems
- Abnormal eye movements
- Blurred or double vision/loss of vision
- Behaviour change
- Fits or seizures
- Delayed or arrested puberty

If you or your child has one of these, see your doctor, if two or more, ask for an 'urgent referral'

Can you help us further by following and sharing Eleanor's story? It's all we ask, although many have offered far more of which we are eternally grateful. Simply search for the hashtag **#eleanorsvoice** on any social media platform you may use, ie. Google, Facebook, Twitter or Instagram. Give it a try!

It could just convince another parent to finally push for important tests their child might need and at the very least allay their concerns. It could be for any symptom, even minor, but acting sooner rather than later is by far the best option.

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, Tim Stollery - **#eleanorsvoice**