

Ali's Story

The year 2000 approached - a new millennium and a new beginning. New years always made me sad, looking back at our happy life wondering what was ahead.

In May I became unsettled but didn't know why, when my life was so complete. Then I became aware that Alison had **developed a subtle incomplete movement in her eye** that only a mother would notice. I took her to the doctor who referred me to an optician who said it was common and would correct itself.



Gary and I would talk and talk about it. I knew something was wrong. I went back to the doctor then to another optician. **"Please someone listen to me"**. I started to make Gary nervous. He knew I knew the children so well.

I went to a third optician - Gary was on a school trip with one of the boys but I went on the spur of the moment. I hated this **feeling in my stomach telling me to act and act now!**

They did test after test, and then told me to go to A&E with a letter that something was making the muscles in her eye deteriorate. Gary was only 5 minutes away; we dropped the boys off and went to the hospital. They said they couldn't see anything but told us to go to a leading eye hospital the next day.

A sleepless night. Gary and Matthew were due to go on a school trip for a week on the Sunday, which was Ali's 7th birthday - what were they going to find. They told us it was nothing, that the slight squint had always been there - that I was paranoid and vain because my pretty little girl wasn't perfect (but to us, no matter what, all our children were always perfect). The feeling it left was even more desperate than before.

While Gary and Matthew were away I would wait until Graham and Alison were asleep then turn my cupboards out looking for photos - any photos - to prove I knew my child and that she had never had a squint until now. Armed with my photos I went back to my GP yet again, he agreed to send me for a second opinion - at least he was listening. The phone calls between Gary and me were desperate and he felt so far away, but we had three children and life had to go on for them all.

Our holiday came and it was perfect: sun, sand and sea in a beautiful villa, **and for the moment, peace.**

Our appointment came through for the end of August (so far off). In the middle of August we could wait no longer, in desperation we took her to the doctors yet again and she referred us to the children's unit at our local hospital for an appointment the next day. "I'm sure it's nothing", she said.

Our hearts had become heavy - two parents who knew their children so well, but kept being doubted.

Test after test - eye test, blood test, "walk along this line"..... Always she laughed and joked with the doctors and nurses, they could see nothing wrong. "To be on the safe side we'll do a scan", they said. This scan destroyed us. We couldn't breathe - the words were buzzing through us. Holding hands we were watching through the glass of the doors, our 3 precious babies making faces to make us laugh...but the laughter never came.

THEY FOUND A TUMOUR - A BRAIN TUMOUR.

We went to my parents' house. The world was spinning; how to act normal for the children; how to function, how to cope.

We had to go to Great Ormond Street Hospital (GOSH), but not today, next week, the consultants don't get together till next week. They only meet on a Tuesday, **wait, wait, wait -**

DON'T THEY KNOW THAT THIS IS OUR CHILD? She needs another scan – when, today? No not today. Tomorrow? No not tomorrow, another day, **we only make decisions on a Tuesday** – don't they know this is our 7-year old child?

Another doctor at our practice telling us to “pull ourselves together” - **DON'T THEY KNOW THAT THIS IS OUR CHILD?** Telling ourselves: Don't let the children know – we have to protect them all. We went to GOSH anyway, we needed to speak to someone.

Armed with our scans and disbelief, my parents took us. They sat outside with Ali while we went in to the specialist. **“There's nothing we can do - the tumour is untreatable”** the room's gone black and I'm sick in a bucket, strong arms are holding me. My Gary is white and staring. My perfect life has just gone in the bucket. Those strong hands belonged to someone who was to become one of Ali's and our dearest friends - a special nurse called Harry.

What followed is a blur to me....

Radiotherapy followed. Up and down, up and down – **waiting** for trains – **waiting** for appointments – **waiting** to see a consultant, every day for 6 weeks, **she was only 7 years old**. She was so brave and was loved by all the staff. Our family, Gary's mum and dad, my parents all took it in turns to come with us. I can remember it feeling so unreal, but always we kept up the laughter to keep it **normal for the children and the love so much of it, always love**.

Radiotherapy gave us so much extra time: Laughter in Lourdes shared by her Suey and Grandad: Florida such fun and warmth **'TOGETHER TIME'**, an amazing swim with the dolphins - a wish fulfilled. This was shared with Penny, Jon and Ash. **Such special memories**.

Following a great night at the Theatre that she so loved with Mama and Grandad – April brought my birthday and a nightmare - a haemorrhage into the tumour and two months to live - **HAPPY BIRTHDAY**. As she got more and more poorly “her boys” were always at her side, playing with her, helping her eat, fetching and carrying and always loving her - **there was always so much love**.

Such special people were there for us, but life was out of our control - all we could do was watch and continue phoning abroad, desperate to do anything.

Just before her 8th birthday on 7th June 2001, in the early hours **our lights went out - a bulb never to be replaced, a scar never to heal, a hole never to be filled, our jigsaw - a piece missing never again to be complete**.

Like the words of so many songs going over and over in my head – **“I'd walk a million miles for one of your smiles”, “I have a dream, a song to sing”, “This little light of mine”, “It's a mad world”, “I want to thank you for giving me the best days of my life”**. Tears ready to spill and a lump in my throat. A loneliness in a room full of people.

With her love of Dolphins, her big heart and the end of her rainbow is our Ali's Dream. Having lost the fight our whole family is now **united in grief with determination to do something, so that a cure can be found sooner rather than later**.

Julie, Gary, Matthew, Graham – Extract from Ali's Story - www.alisdream.org.uk