

ENUCLEATION



We understand it is shocking news to hear that your child has cancer and then that their eye needs to be removed. However the whole family will be supported throughout the entire process by your treatment team and your Childhood Eye Cancer Trust (CHECT) support worker. While having an artificial eye is a life-changing experience for you all, hopefully you will find your child will adapt very quickly.

This leaflet is not about the process of enucleation itself but about how families have coped with it. CHECT has always asked members to share their stories. We know that it can be helpful and often uplifting to read other people's retinoblastoma (Rb) stories. You will find the full versions of the below extracts, as well as other stories, at www.chect.org.uk.

James was diagnosed with unilateral Rb at two years of age. His mum, Charlie, shares their story.

James was diagnosed with retinoblastoma just after his second birthday, after I'd noticed a strange appearance in his pupil a couple of times. Having been examined at our local opticians and hospital ophthalmology department, we were referred to one of the specialist Rb centres. The consultant and the team of doctors who had examined him explained with compassion that James had unilateral retinoblastoma of the left eye, and that the best and only option we had would be enucleation to prevent it spreading

further. At this point, my world seemed to be falling apart. My heart was lodged somewhere in my throat, tears streamed down my expressionless blank face, as I desperately tried to come to terms with what I was hearing. I was gently reminded "You have saved his life".

We went home with lots of information, and we were given several calls from the nursing staff over the coming days to reassure us and answer questions. James in the meanwhile was his happy-go-lucky self, back at nursery being a typical two year old. Two weeks later we were back at the hospital, given a side room and assured we

Email -
support@chect.org.uk

Lena - London
07706 919 996

Sarah - Birmingham
07526 594 762

Office -
020 7377 5578

wouldn't have a long wait. James enjoyed playing in the play room whilst we waited and it was a good enough distraction from him being hungry. When James went down to surgery, I walked him down the corridor with the nurses and play therapist, blowing bubbles

for him to chase and spotting the spacemen on the walls. James sat on my lap whilst he was administered his anaesthetic. This moment right here was the worst I'd felt through our whole journey (and it still is).

What seemed like days later, (actually a couple of hours), we were taken to the recovery room to be by James' side when he woke up, which he did briefly and fell back to sleep. The surgery had gone extremely well and James and I were moved to the children's ward in the main part of the hospital to stay the night. The nurses reassured me that by the morning he would be asking to play in the playroom again... Low and behold at 6.15 the next morning James was awake, asking for breakfast and to watch Peppa Pig. I was astounded by his resilience. He was dressed and playing in the playroom after breakfast, sporting his bandage, ready to take on the world as he had done before. Almost exactly 24 hours later James' bandage was removed and we couldn't have hoped for anything better: he had no swelling or bruising. We were told it may take some time for his eyelid to open, but with those words he opened his eye. The relief

was immense for me. I don't know what image I had conjured up in my head to prepare myself for the unknown, but apart from being not quite the same colour, his eye looked as it had before. 45 minutes later we were on our way home.

Six weeks later on March 22nd we had our first appointment with the National Artificial Eye Service for James' conformer (an artificial eye with a small hole in which was fitted during surgery) to be removed and his first eye to be fitted. It was a bit of a battle of wills but James enjoyed helping to choose the best colour match and was fascinated by the process. The relationship between James and his prosthetist has continued to grow and James has a trusting and honest relationship with him. Three months later James received his first molded eye, which was a huge milestone for us. He had developed a notion of not wanting to give up his prosthetic eye in case he didn't get it back. We have found the questions James asks have changed as he matures. We chose to be completely honest with him from the start, in the hope that as he grew older he

would know the answers we gave are truthful, even the difficult ones.

James forever goes on to show us how incredible he is. Now in his second year of primary school he is full of life, and such a character – he is as daring and courageous as my nerves will allow! We have learnt so much on our journey. Whilst our Rb story wasn't one we would have chosen, we are thankful for the treasures it has allowed us to see, for the support we have been given, and for the lifelong friends we have made.



Jude was diagnosed with unilateral Rb at nine months. His mum, Jodie shares their story.

The night before the operation I was terrified that Jude wouldn't be the same after the surgery and that I would feel differently about him. We took lots of photos of him that day, as if trying to preserve our baby.

I was so relieved that my fears were completely unfounded. Of course he was still my baby, my Jude, and my feelings for him were utterly unchanged.

With a retinoblastoma diagnosis everything happens so quickly, particularly if the treatment is enucleation. We found we were running on adrenaline for weeks afterwards and it wasn't until we got the news that the surgery had been successful and no chemotherapy was required that my emotions caught up with me.

Telling people about Jude's diagnosis was incredibly hard. Our family and friends were extremely supportive, but often people didn't know how to react or what to say. The word 'cancer' makes people scared and feel awkward at the same time. Often we found ourselves comforting those we had told rather than the other way around. So many times we listened to people tell us that they didn't know how we coped so well. Whether or not we coped well is subjective, but ultimately when you have a child you have no choice but to cope and to carry on. Your love for them is what carries you through as they need their parents to be there for them in every way possible.

Two years on and Jude is doing brilliantly. His artificial eye is looking great and the fittings haven't been the battles that I feared. Occasionally he objects to his eye being cleaned, but only as much as he objects to a nose wipe or having his teeth brushed.

My advice for anyone going through the agony of diagnosis now would be to try to find the positives and focus on them, but to be kind to yourself and allow yourself plenty of time to come to terms with what has happened and for your emotions to catch up with the fast pace at which treatment moves.

To hear more from families whose children have gone through enucleation you can visit the CHECT website, join our closed Facebook group for parents, or ask your support worker to link you with another family.

We asked some parents what they wished they could have told themselves before the surgery, here is what they said:

- The day after my boy's operation he was sitting colouring, playing with toys. He wasn't in any pain at all. He was three when he had the enucleation: he's now almost seven, and he's had a normal, happy childhood. It has never held him back and never will. It really isn't the end of the world, and your child will still be the same happy child, no matter what.
- I remember feeling like I was losing my child 'as she was' forever, and that I would somehow feel differently about her. I had an urge to take lots of photos before the op to try and 'preserve' her somehow. After enucleation I quickly realised all my fears were completely unfounded. My daughter was just the same as before, I felt exactly the same towards her, and I can honestly say the only time I looked back at those photos was when we stumbled across them moving house.
- It never stops them doing what they want to do. My daughter learned to ski at five. She is amazing.

- They get over it really quickly – your child is a lot tougher than you may give them credit for! You may feel very emotional. If you need to cry then do so and don't feel ashamed – you are not superman/woman.

- My son's way of dealing with everything was to refuse to take his medication! We had to think of creative ways to get him to have his medicine – a small amount of strong squash and medicine with the promise of something nice after!

- It is much harder on the parents than the child. Our son was more bothered by the cannula in his hand than the fact his eye had been removed! Also, his artificial eye looks amazing – people can't tell the difference between his eyes.

- I wish I could have told myself that six years later no-one would even notice her magic eye and that life is now completely normal.

- I had my eye removed at about four months old. As someone who is now 23, it has stopped me from doing nothing except

driving (I had tumours in both eyes, though only one had to be removed thankfully). I got my GCSEs, A Levels, a degree and now work as a teaching assistant, hoping to be a teacher one day. I had days as a child and teen where I longed to be 'normal', and the not driving was upsetting, but I have realised it really hasn't stopped me from accomplishing anything.

- I wish I knew that when she got older (she was two months at enucleation) she'd be fearless and strong and want to do anything and everything. We all saved her life and she lives it to the full. Losing an eye has yet to prevent her from doing anything at all.

After surgery sometimes your child's eye area may look bruised and/or swollen for a few days. Parents told us how they tackled this when out and about.

- I was angry at first when people stared, but then I started to explain what had happened so that more people in the world would understand.

- We counted to 10 and then

explained to them. The staring stopped and they went away with something to think about and hopefully pass on to others!

- Sending a mass email to parents in both my son and his brother's class was one of the most effective ways for us to let people know what had happened. We showed them a photo of my son and his new eye (which was amazing from the start). Using email also helped us having endless 'half' conversations in a busy playground environment.

- Two days after surgery my son was running around and playing on his bike with his friend. The third day we went into town (everything was raw, emotional and frightening for me). He was his normal self only he had the worst black eye imaginable! I can remember every look I got that day. We went for an ice cream and the lady serving said 'Oh dear, what happened? So I explained he had cancer and had to have his eye taken out. She said he was such a brave boy she would buy the ice cream for him. I thought she was brave for asking, and I've never forgotten that day.

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