

Enucleation

(Surgical removal of an eye)



We understand it can be devastating to hear that your child has cancer and then that their eye needs to be removed. A CHECT support worker is there to listen to your concerns and can link you to someone who has been through it. 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 told us they coped with it. We asked some parents what they wished they could have told themselves before the surgery, here is what they said:

- It never stops them doing what they want to do. My daughter learned to ski at five. She is amazing.
- They are who they are today not despite the enucleation, but in part because of it, I believe it has only added value to his life, he is so good and brave and sensible now at five and I am so proud of him.
- The day after my boy's operation he was sitting colouring, playing with toys and didn't complain one bit once he wasn't in any pain at all, he was three when he got the enucleation and he's now almost 7 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.
- As a grandparent, I'd like to let other grandparents know their own child will probably suffer more emotionally than the small child going through the operation. It's scary and when you don't know what's happening the worst comes to mind. But rest assured the little child is strong and will live normally after. No one knows one eye is a prosthetic - and those who do know can't figure out which one it is!
- They get over it ridiculously quickly - your child is a lot tougher than you may give them credit for! Expect to be an emotional wreck, if you need to cry then do so (when your child can't see!) and don't feel ashamed - you are not superman/woman.

“I wish I knew that when she got older, she would be fearless and strong and want to do anything and everything.”



- Expect sickness because of a longer anaesthetic and a long night post enucleation. My son's way of dealing with everything was to refuse to take his medication! Had to think of creative ways to get him to have his medicine - small amount of strong squash and medicine with the promise of a proper drink after moving onto small strong flavoured fruit juice and meds!
- I wish I knew that when she got older (she was two months at enucleation; now two-and-a-half years) she'd be fearless and strong and want to do anything and everything. We all saved her life and she lives it to the fullest. Losing an eye has yet to prevent her from doing anything at all.
- 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 six years later that no one would even notice her magic eye now and that life is completely normal.
- I had my eye removed at about four months old and 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 went to state school, got my GCSEs, A Levels, a degree and now work as a teaching assistant and 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.

My Story

CHECT has always asked people to share their stories. We know it can be helpful and sometimes uplifting. We have an extract below. You can find the full 'My Story' on our website.

Julie Firth's story

Isla was diagnosed with unilateral Rb and the tumour had already detached the retina, rendering her effectively blind in one eye. At two, she had, unbeknown to us, already adjusted to life with monocular vision. But in

the days leading up to the operation I couldn't get past the overwhelming sense of grief I felt knowing a part of my gorgeous girl would soon be lost forever.

“Hour by hour Isla regained her strength and by lunchtime the following day, she was jabbering away again as if nothing had happened.”



I worried whether I would feel the same unconditional love I felt now, or would that be tainted in some way. I even arranged for a friend to take some professional photographs of her, so I could cherish the memories of how she once looked.

A week after diagnosis Isla went back to Birmingham for the enucleation. We stayed over in the hotel the night before and took her to the ward early the next morning. The nurses were friendly and reassuring, the Rb team took time to explain exactly what would happen and were on hand to answer any questions.

The play specialist helped us keep Isla occupied, giving us the chance to compose ourselves. When Isla went down to theatre, it was without a doubt the worst two hours of my life waiting for her to emerge.

But any doubts of how I'd feel about her after the operation disappeared the second I saw her in recovery, with a big patch over her eye. I barely slept that night by Isla's bed, I hung on her every breath, held her when she woke and comforted her when she got upset.

Hour by hour Isla regained her strength and by lunchtime the following day, she was jabbering away again as if nothing had happened. By tea time she was tearing up and down the ward to our amazement - my husband and I both knew neither one of us could have bounced back quite so dramatically. Then to

our astonishment, a little over 24 hours post operation, she was discharged.

We stayed at the hotel again that night, glad to have the hospital nearby, but by morning we felt confident we could make our way home. The bandage came off a couple of days later and Isla's eye was bruised and swollen but by the end of the week we had our first glimpse of the new 'eye'.

Ten days later we received the news that the tumour had been contained and she would not need chemotherapy. I remember feeling like we'd won the lottery.

Six weeks marked a major milestone as Isla was fitted for her first artificial eye - a great match - and she was also given the all clear to go swimming again. She couldn't wait to try out her new pink goggles!

We recorded every step of Isla's journey, with pictures in hospital, and in the days and weeks following, so one day we can show her what she went through and remind ourselves just how brave she was.

Isla is now six, is excelling at school, goes to Kung Fu, swimming and Zumba and she learnt to ride her bike properly last year.

While it felt like the end of the world for us four years ago, Isla has proved there was no way she was going to let Rb stand in the way of her enjoying life to the full.

“Sending a mass email to parents in both my son and his brother’s class was the most effective way for us to let people know what had happened.”



Editor’s note:

The time until the bandage is removed and the age of discharge can vary and depends on each individual case, diagnosis and treatment. Read Julie’s story in full and other accounts in the My Story section on our website www.chect.org.uk under [Parents](#). Isla’s own account can be found in the [Children aged 1-6](#) section.

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 the most effective way 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? Have you been falling? 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.
- Un-notice the people that stare, but remember if they do they are looking out for your child, curiosity is a good thing, if it can be answered with truth and honesty.

Useful booklets

Visit our website for a list of booklets for families with children who have an enucleation.

Out of hours support

Our forum, website and Facebook page are all resources you can use outside office hours.