

## Six year old James joins charity's Christmas appeal as thanks for keeping his family by his side

Thursday 7 December, 2017

Just after his fifth birthday, James was diagnosed with retinoblastoma. Since then James has undergone chemotherapy and attended The Royal London Hospital where he had to have his eye removed. The Sick Children's Trust has supported James' family at Stevenson House during this time. And as a thank you, James and his family have joined in The Sick Children's Trust's first ever Christmas appeal! Mum Helen Harrison tells their story:

"We had just celebrated James' fifth birthday before our 'normal' family life became a different type of 'normal'.

"James had gone to school and on that day they were doing the children's eye tests. I received a call to say that the school nurse was a little bit concerned as when they covered James' right eye, he was looking all around and seemed to be struggling to see. They advised me to make an appointment at our local opticians, so I did.

"As I waited for James' eye check to be done, I didn't have any huge concerns. But then the optometrist called me into the room. He was very calm, but I could tell he'd discovered something serious. He said that I should take James to the local eye hospital for a further appointment.

"Although he was calm, he must've been secretly panicking because within no time at all I received a call from our local hospital saying I should bring James in immediately. We were there for three or four hours while James underwent test after test. I was finally told that they thought James had a rare eye condition called Coat's disease, which effects the smaller blood vessels in the eye.

"The doctor referred us to The Royal London Children's Hospital – which specialises in paediatric eye conditions. When we went down for our appointment, James was put under a general anaesthetic so they could have a full look at his retina.

"James' dad, Andy, and I waited outside for news. When the team had finished, we were taken to a private room where we were told that James didn't have Coat's disease, he had retinoblastoma. Our son had cancer.

"I will never forget the feeling of complete shock as I was told that my son had eye cancer. I had never heard about the condition and it was so hard to get my head around what they were telling me – it was mind boggling. We were being told lots of information that really, we didn't want to hear. But equally we needed to know.

"James had a 70/30 percent chance of saving his eye if we underwent chemotherapy, so we decided we would. For a year we attended Alder Hey Children's Hospital in Liverpool for his treatment and every few months we had to travel to London for check-ups to see if the chemotherapy was working. James needed to be put under general anaesthetic every time. Fortunately we didn't have to travel all the way back to Cheshire because the hospital contacted The Sick Children's Trust charity who offered us free accommodation at its Stevenson House, which is just a few minutes' walk from the hospital.

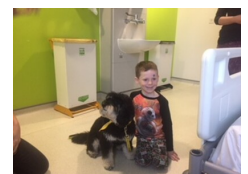
"We've stayed Stevenson House four times since James' diagnosis and it's really been a huge help, especially as James' younger sister, Amelia, has also had to undergo general anaesthetic to see if she had retinoblastoma too. Having two children in a hotel room would've been a nightmare. At Stevenson House, even though we were far away from home there was so much space for the kids and they could keep busy in the playground.

"For us though, above all else Stevenson House has given us a sense of security and allowed us to be a family which during this time has been so important.

"At first, James' body responded well to the chemotherapy, but despite our hopes that we would be able to save James' eye, in February this year we were told that the tumour had regressed and there was no option but to remove his eye.

"A week later we were down for the operation – and because of Stevenson House it meant that James could have us both there – his dad and me. I slept on the ward the night of the operation and Andy was

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just a few minutes away at Stevenson House, which was comforting for James to know that his dad wasn't too far. And it was comforting for me too.

"It began to seem like the odds were against us as even though James had his eye removed, there was still a 50/50 chance that the cancer had already spread. So James had to undergo another four courses of chemo up until June this year.

"Despite all he's been through – James has been unbelievable and continued to have a smile on his face. We've had a few bumps along the way as he hates needles and going under the general anaesthetic, but he's really done us so proud. And it's because of his strength that we've found it so much easier to cope.

"When we first told about James' condition, there were a lot of tears, and I remember speaking to my dad who told me that we just had to make this – the hospital visits, the chemotherapy, everything – our new normal. We just had to get on with it. And we could because of all the support we received from our family, friends, The Sick Children's Trust, but more so because of James and his attitude towards it.

"James very much normalises what he's been through. He recently went on a camping trip and I asked him if anyone had mentioned anything about his eye. He said they did and he just told them it was plastic and to get on with it! James is currently having moulds done so that he can get a prosthetic eye. Originally he wanted one with the Star Wars 'death star' but since going on a weekend away ran by the Childhood Eye Cancer Trust where James met lots of other children with retinoblastoma, he saw one child with a Man United eye and now he's very keen for one of them!

"James will have to have eye checks every six months until he's 18 years old, when he will then go annually. But to know that when we have to go to London, Stevenson House is there for us is a huge relief. When you have to starve your child before they go under general anaesthetic is extremely hard, but to be able to say to them 'what would you like for tea?' and be able to make their favourite meal, is what makes The Sick Children's Trust's 'Homes from Home' so special.

"When your child is ill, you just hope that when they're older that they understand the decisions you have made. Thankfully for us, James already does."

The Sick Children's Trust is a national charity which supports around 4,000 families every year. The charity relies entirely on voluntary donations to keep its ten 'Homes from Home' running, providing vital support to families with children undergoing lifesaving treatment in hospital. This Christmas it expects that every room in every house will be full with families, caring for some of the UK's sickest children.

**Jane Featherstone, CEO at The Sick Children's Trust says:** "No child should wake up on Christmas morning without their family around them. But this Christmas, many families with a critically ill child in a specialist hospital will face a long journey to be at their child's side.

"A donation of £30 will give a family a place to stay in one of our 'Homes from Home', just moments from their sick child. It costs The Sick Children's Trust £13,140 to run our ten 'Homes from Home' across the country over the Christmas period, keeping families together at one of the most important times of the year. Your donation can make this possible."

To keep a family together this Christmas, please visit:

<https://www.justgiving.com/campaigns/charity/sickchildrenstrust/alliwantforxmas>.

To watch the Christmas appeal film, visit: <https://youtu.be/qpgKkZuPWmc>.

For more information on The Sick Children's Trust and for other ways to donate, please visit <http://www.sickchildrenstrust.org/Donate/>

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