Trust a parent’s instinct, charity urges GPs

Tuesday 28 February, 2017

GPs are being urged to trust a parent’s instinct after new figures* show that babies and children are waiting more than three times longer than the recommended guidelines to be diagnosed with a form of childhood eye cancer.

In 2016 the average time from a child’s first visit to a healthcare professional to being seen at a specialist centre for retinoblastoma was seven weeks. The National Institute for Health and Care Excellence (NICE) guidelines state that a child should be referred urgently and seen within two weeks if retinoblastoma is suspected, but 64% of children waited longer than this, with 32% waiting over two months. Many families have to make several visits to their doctor or other healthcare professional before the appropriate tests are carried out.

Retinoblastoma is a fast growing cancer that affects young children, mainly under the age of six, and early diagnosis is essential in order to save a child’s eyes, sight and life. Sadly, more than 70% of children will lose an eye to stop the cancer spreading.

Today, to mark Rare Disease Day (28 February) the Childhood Eye Cancer Trust has urged parents and healthcare professionals to be aware of the symptoms.

Patrick Tonks, Chief Executive of the Childhood Eye Cancer Trust, said: “Retinoblastoma is rare, with around 50 cases diagnosed in the UK each year, so most doctors will never come across it in their career. In addition to this, the symptoms are very subtle and children often seem well in themselves which makes it hard to diagnose. But this is leading to alarming delays and we know that early diagnosis can potentially offer more treatment options and a better outcome for the child.”

The two main symptoms of retinoblastoma are a squint and a white glow in a child’s eye, seen in dim lighting or when a photo is taken using a flash. Healthcare professionals should carry out a red reflex test on any child showing these symptoms in order to rule out cancer.

This is a simple, non-invasive test which is done using a medical torch in a darkened room to check the retina at the back of both eyes. If eye cancer is suspected, an urgent referral should be made (within two weeks), according to the NICE guidelines.

However, the latest figures show that in 2016 only 38% of GPs made an urgent referral after seeing a child who was later diagnosed with retinoblastoma. In contrast, 88% of children who were taken straight to A&E were referred urgently.

Patrick said: “Parents tend to have a second sense when it comes to their children and are often the first to know that something is wrong, so we urge GPs to factor in parental concern when deciding whether to refer. And mums and dads can often be afraid of being branded a paranoid parent but our message is, if you have any concerns about your child’s eyes, ask your doctor to carry out a red reflex test. Don’t be afraid to speak up.”

‘GP trusted our instincts – and we saved Charlie’s eye’

Charlie Boggs was just 10 months old when he was diagnosed with retinoblastoma in April last year. His parents, Gemma and Andrew Boggs, first noticed a white glow in his eye one night when changing his nappy. After seeing the glow twice more, they took him to the GP.

Gemma, 35, from Glasgow, said: “We first saw this strange white glow in Charlie’s left eye when we were visiting Andrew’s parents for Christmas but we put it down to the different lighting in their house. But we saw it again one evening when we got home and then another time when we took him swimming, so we went online and googled ‘glow in baby’s eye’. Among other things, up popped a page about retinoblastoma.

“We read that retinoblastoma was very rare and that there was a tiny chance of it being that, so we weren’t too worried but we wanted to get it checked to rule out anything serious.”

At the appointment the GP couldn’t see anything unusual about Charlie’s eyes. He asked Gemma questions about Charlie’s behaviour and whether he had been bumping into anything, which would suggest a problem with his eyesight, but all signs pointed to Charlie being a happy, healthy little boy.

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Gemma explained what she had read about retinoblastoma and showed the GP the one photo she had out of hundreds with a white glow. The GP went online to read about the symptoms himself and then examined Charlie's eyes again in a darkened room.

Gemma said: "Although the GP still couldn't recreate the white glow, he knew that we were concerned and referred us to the local hospital eye department in Glasgow who saw Charlie two and a half weeks later. They examined his eyes and told us almost straightaway that it was very likely cancer and that he needed further tests urgently. We literally went home, packed our bags and were at the train station the following morning on our way to the Royal London Hospital, one of the two specialist centres for retinoblastoma in the UK."

The following day Charlie was put under general anaesthetic so that his eyes could be examined thoroughly, which confirmed he had retinoblastoma. Gemma said: "The doctor said that, because it had been caught when it had, there was a 60% chance of saving his eye, and that they would try to save what sight they could but that he was unlikely to have good vision in that eye."

At just 10 months old, Charlie endured six rounds of chemotherapy, which finished in September last year. So far the treatment has been successful and he is now stable, although the family have to travel to London from Scotland every six to eight weeks for check ups.

Gemma said: "I am 100% convinced that if the GP had told me there was nothing to worry about and sent us home, it would have been months before we would have taken him back again and we are almost certain he would have lost an eye. Despite the fact that Charlie seemed perfectly well and healthy and there was nothing to suggest anything was wrong, the GP trusted our instincts and as a result, we have saved Charlie's eye. We cannot thank him enough."

Charlie, who turns two in June, is now a typical toddler who loves playing and making new friends. Gemma said: "Charlie has been an absolute star throughout his diagnosis and treatment. We were told he would probably lose his hair and feel very poorly and we prepared for the worst but he took it all in his stride and kept everyone around him going."

"He is such a fun, sociable little boy who is into everything and is a joy to be around. He is very chatty and has always got a story to tell. We are so proud of our little boy.

"When Charlie was diagnosed family and friends asked how they could help us. Initially Andy and I were unsure but quickly realised that they could help others to help Charlie. The support we have all received from the wonderful staff at CHECT and others (The Sick Children's Trust and Glasgow Children's Hospital Charity) has been absolutely invaluable during his cancer journey. Through Charlie's Big Adventure JustGiving page we have so far raised almost £5,500. Every penny donated to these amazing charities helps Charlie and others just like him."

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