Too many children are still waiting too long for cancer diagnosis

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One in ten babies and children in the UK with an aggressive type of eye cancer have to wait more than six months to be diagnosed, according to new figures*.

The Childhood Eye Cancer Trust (CHECT) found that 11% of children diagnosed with retinoblastoma in 2017 had a delay of at least six months from their first visit to a GP or other health professional to being seen for specialist assessment.

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.

In 2017, 57% of children were referred urgently for specialist assessment and were seen within the recommended 2 weeks, up from 40% in 2016. However, 43% of children waited longer than this, with 11% waiting over six 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 white glow in a child’s eye, seen in dim lighting or when a photo is taken using a flash and a squint, where the eyes do not look in the same direction. 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 2017 only 36% of GPs made an urgent referral after seeing a child who was later diagnosed with retinoblastoma.

“It was horrible thinking that something was wrong but not knowing for sure”

Logan Brown was just 2 years old when he was diagnosed with retinoblastoma in August 2017, after his parents noticed a white glow in his left eye whilst Logan was playing.

Hayley, from Wisbech St Mary, Cambridgeshire, said: “We first saw a strange white blur across Logan’s pupil when he was playing, and again when we were putting Logan to bed. We though it was odd so went online and googled “white blur in child’s pupil” which led us to information about retinoblastoma on the CHECT website.

“We read that retinoblastoma was very rare but we could see that it was important to get Logan’s eye checked out straight away.”

The following morning Hayley tried to get an appointment at a local opticians but, despite explaining why she wanted an appointment for her son, was told that Logan was too young to see, so immediately made an appointment with the GP.

At the appointment with the GP, Hayley explained she had read about retinoblastoma and showed the GP some photographs of Logan, she had taken with flash whilst waiting for the appointment, which clearly showed a white glow in his left eye. The GP examined Logan’s eyes, carrying out a red reflex test

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in a darkened room, and made an urgent referral to the local hospital eye department.

When the appointment came through it was for 8 weeks later, Hayley rang the hospital straightaway to ask for an earlier appointment or cancellation and was told neither was possible. Concerned Hayley returned to her doctors' surgery and saw a second GP who, without carrying out a red reflex test, told her not to worry and to wait for the appointment at the local hospital eye department.

Eight weeks later, the appointment at the local hospital finally arrived but the ophthalmologist was unable to say what was wrong and Logan was urgently referred to see a more senior ophthalmologist at Addenbrooke's Hospital.

Hayley: "It was really hard, we know now retinoblastoma is really rare and not every health professional will have seen it, but we were so worried, we could see the white glow more clearly each day and it was horrible thinking that something was wrong but not knowing for sure".

Two weeks later the family went to Addenbrooke's Hospital, only to have to return a week later to have Logan examined under general anaesthetic. Suspecting retinoblastoma, the ophthalmologist referred the family to The Royal London Hospital the following day, one of the two specialist centres for retinoblastoma in the UK.

At The Royal London Hospital, Logan was diagnosed with unilateral retinoblastoma. The following week Logan had his left eye removed, the operation was successful and Logan required no further treatment.

Logan, who turns three in May, is now a typical cheeky toddler who loves playing and making friends. Hayley said: "Throughout all of this Logan has carried being his cheeky, mischievous, little self and taken it all in his stride. We are so proud of our little boy"

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