

### Maalik's story December 2023

**Name of service:** Children's Nursing – part of the Expert Children's team.

**Main purpose of service:** We specialise in assessing and treating children. We treat a wide range of conditions using specialist skills to maximise independence and function of the child and to support their families.

**About the person:** Maalik will soon be 2 years old. When he was 3 weeks old, his parents found a soft lump at the base of his spine. An ultrasound



was inconclusive, so Maalik had an MRI scan. Mum Fizah explains what happened next. **“The day after the MRI scan, we had a call telling us something was wrong with Maalik's kidney. We had to go to Pinderfields Hospital. I remember we were feeding the kids lunch, but we were there within half an hour!”** The family were told that the scan had detected a 6 cm tumor on Maalik's adrenal gland. **“It's what is called an ‘incidental finding’, as he had no symptoms, other than being very sleepy.”** Multiple tests and investigations were organised by the Oncology team in Leeds. The family were told that the ‘neuroblastoma’ may shrink and disappear without treatment, however genetic testing of the cancer cells in the tumor suggested this was unlikely. **“I remember it was the start of Ramadan. The test results came back, and we were told that Maalik did need treatment after all. It was really shocking as we'd been so hopeful that he wouldn't.”**

**Treatment:** Maalik needed four courses of chemotherapy, which meant going to Leeds every three weeks for treatment. A Hickman line was put in place. This is when a flexible plastic tube is inserted under the skin of the chest wall and into the large vein that drains into the heart. The family were visited by Locala's nurse Hannah who regularly cleaned Maalik's Hickman line site and changed his dressing. **“Every week Hannah, or her team, visited without fail. They were so patient with him. My kids got so used to her, we'd look forward to her coming!”**

**Surgery:** Despite the chemotherapy, the tumor didn't shrink as hoped and in August 2022, surgery was recommended. The operation was successful, and all the tumor was removed. Maalik now has regular scans and tests to check that his kidneys remain healthy. Fizah says, **“As the scan date approaches, you get anxious.”** She continues, **“The lump at base of the spine is a separate issue – it's a large mass of tissue where the spine is underdeveloped. It's monitored regularly too. It's really positive that he is now walking!”** The lump at the base of Maalik's spine was diagnosed as ‘lipomyelomeningocele’.

**Care and support:** Fizah explains that Hannah did so much more than care for the Hickman line site. **“She sorted out supplies. She helped us with disability allowance. She contacted the housing department, and this helped us move to better accommodation. She would ask me, ‘How is it for you?’ She felt like someone I could turn to. Olivia too. The nurses were there for everything. Emotional support. Hannah became part of our family. She really gets invested. It's not for show – she's genuine! She even got a holiday for us!”**

**Family Holiday:** Fizah explains how caring for a poorly baby undergoing chemotherapy and attending multiple hospital appointments effects the whole family. **“Since Maalik was born, we'd felt stuck. It was like we'd all been on hold for a year. It can get difficult for the other kids.”** Hannah made a request on behalf of the family to ‘Ruddi's Retreat’ for a holiday at Primrose Valley Caravan Park at Filey. Maalik and his family went in May 2023 and enjoyed a week in a caravan. Fizah says, **“It was amazing. The kids loved it – they loved the beach!”** For more details see [Ruddi's Retreat \(ruddisretreat.org\)](https://ruddisretreat.org)

*Maalik's Mum Fizah spoke with Joanne from the Engagement Team on 5.10.23 and gives full consent to share Maalik's story*