



Yusuf is cared for at Acorns in Birmingham. From this hospice we provide support to children and families across Birmingham, Solihull, Coventry and North Warwickshire.

*"Yusuf is a little cutie pie,"* says mum Iram. She's right. His big beaming smile greets everyone who meets him. He is one of 6,000 children born in the UK every year with a syndrome without a name – a condition so rare it remains undiagnosed. But it means his life is limited.

Yusuf's complex care needs were discovered during the first week of his life. Iram had taken her newborn son home and knew something wasn't right. Her middle child Musah had passed away from an undiagnosed condition two years earlier. Yusuf's dramatic weight loss was alarmingly similar.

*Iram said: "You couldn't tell when he was born. He was absolutely fine, a healthy baby. But when we brought him home, he'd lost 10% of his weight and I just knew something was wrong, I could feel it."*

*"We took him to hospital and the same consultant who looked after my other son was there and I'll never forget the look on her face. They'd tested Yusuf's blood. I looked at her and she nodded her head, she didn't have to say anything. I knew Yusuf had the same condition as Musah."*

*"My whole world stopped. My other children had been born healthy and fine and I just didn't think it would happen to me again. But Yusuf has amazed me."*

*"His condition is life limiting and will eventually lead to kidney failure but he's active, he does well with his feeds, he sleeps through the night – he's doing really well. I'm proud of him."*

The family's journey with Acorns began in early 2020, as the coronavirus crisis swept the globe. Over the past 18 months they have visited their local hospice, Acorns in Birmingham, to enjoy time together, making precious memories and having fun in a safe and secure place.

They come to the hospice for important hydrotherapy, family splashes and music therapy and especially enjoy our Stay and Play sessions.

*"There is no other place like Acorns for children like Yusuf. We go swimming together in the pool. We have messy play sessions with other children. And I have a whole fridge covered in artwork we have created together. I like to show it off to my family and friends."*

*"Yusuf loves it at Acorns and seeing him smile and do things he couldn't at home just makes me so happy. It may sound small but doing things together and filling his day with fun means the world to me."*