

James' Story

A misdiagnoses, cranial surgery, and nearly 15 months of helmet therapy are a lot for anyone to go through at any age, let alone a two-year-old. However, this is exactly how James' journey would pan out after his elongated head shape was pointed out by his health visitor at his 8-week check-up. James' mother, Louise, quickly sought medical advice, but the long road ahead would not be a smooth one.



Case Study

James



James' craniosynostosis story began in 2021, at just eight weeks old. His health visitor noticed that his head was growing in the front and back but remained flat on the sides giving it an elongated appearance. Acting on advice from the health visitor, Louise went to their family GP and successfully sought a referral. A short delay later due to the pandemic, they were seen by the first paediatrician and received diagnoses of "a large head". James' head was indeed measuring larger than normal, and Louise wasn't satisfied with the request to see him again in 6 months, so she sought a second opinion.

She said, "I'm a little bit of a geek. I quite like research and when I was investigating the symptoms, it kept coming up with Craniosynostosis, a condition I'd never heard of before. We had to seek a second opinion as we were unhappy with the diagnosis of simply 'a large head'. During the appointment with the second paediatrician we had to be quite firm and ask them to explain why it was not Craniosynostosis. This is when the paediatrician agreed to a referral to Leeds."

Feeling like they were just about at their wit's end and preparing to fight for their son's health again, the family visited the Leeds specialist craniofacial team.

Within four weeks, Louise's suspicions were

confirmed and James was diagnosed with craniosynostosis. They were then officially referred on to the Craniofacial Team at LGI where they met Steeper Cranial Orthotist, Kate Chauhan. Louise said,

"We met Kate in the corridor and she was the first person that spoke to me. I was apprehensive as you can imagine. I didn't know what we were going into, whether we'd have to fight our case again, or whether were we going to be believed this time. But Kate put me at ease before I even got into the room."

Craniosynostosis is a rare medical condition in which one or more of the sutures in a baby's skull fuse too early, altering the natural growth of the head. As a result, the baby's brain may not have enough space to grow properly, leading to potential developmental issues and increased intracranial pressure. The condition affects roughly 1 in every 2,500 babies and is sadly often misdiagnosed. They finally had a diagnosis and knew they had to act fast. The

craniofacial team and Kate presented the family with three treatment options:

1. An immediate craniectomy followed by STARband helmet therapy until the age of 18 months,
2. Two rounds of surgery to have springs fitted into the skull and subsequently removed later on,
3. Or a full cranial vault reconstruction at 18 months old

As with any medical procedure, each option came with its own risks and considerations. Not only did they want the best possible outcome for James, but they also had to consider the effects the experience would have on his older brother, William. Louise said, "William's not much older than James, and although James is still in his helmet now at 18 months old, we're hoping that in the future, neither of them will remember it in a negative way. Whereas if we'd gone with cranial vault reconstruction, he'd be due to have the surgery now and I think it would've been hard for a four-year-old to see his little brother go through that, compared to a two-and-a-half-year-old. But that's part of why we chose to go with Steeper and the helmet therapy." A decision that would reshape not only James' head but his entire life trajectory.

"All William's ever known is that his brother wears a helmet. My friend has a little girl and one day he asked me, 'When does baby Elsie get her helmet?' He thought all babies got to have helmets! So we had to explain that James



Moulds of James' changing head shape throughout his STARband helmet therapy.

wears one because he's quite special. It was adorable, but at the same time, it broke my heart because he thought it was normal."

In a fortunate turn of events, post op cranial remoulding was introduced as a funded treatment under the NHS in 2021 meaning James could get his treatment and the family didn't have to worry about expensive medical bills. So, on January 27th, James had a 4cm x 10cm piece surgically removed from his skull, and soon after that, his STARband helmet therapy began. The difference in his frontal bossing was noticeable instantly, and just a few months on, his head was completely healed! Louise said, "He's got a little scar that goes right across his head just slightly above his ears, but that's completely healed and now it's a beautiful, perfectly round shape. If he didn't have his scar, you wouldn't have known that he had a full surgery."

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Louise, James' Mum



James has now completed his STARband helmet therapy treatment, and the results have already proved life-changing. The family were told there are no signs of intracranial pressure and specialists have no concerns about potential difficulties in his future such as his eyesight or development being affected. However, he will continue being monitored until he stops growing. James can now look forward to a bright

future with normal development and an adventurous spirit.

When asked how James responded to having to wear a helmet 23 out of 24 hours in a day, Louise said, *"He's completely happy with it. To be honest, I think he's going to do more damage when he comes out of his helmet because he's so used to having this extra layer of protection on his head. He's been learning how to walk recently, and if he falls over, it hasn't hurt him. He also loves the clicking sound of the helmet, so he bounces under the dining table and makes the helmet 'click' off the table underneath. He just giggles, but for most children, that would hurt a little. He's so happy with it that if we take it off, he'll look for other helmets. He'll pick up his brother's bike helmets and try to put them on because that's what he's used to, it's what he knows."*

As James gets older, he may want to have a specific hairstyle to hide his scar, but it will forever serve as a reminder of the strength and resilience that he and his family displayed throughout this challenging journey.



Kate completing a smart sock scan of James' head for his new helmet

Craniosynostosis (cray-nee-oh-sin-oh-sto-sis) is a condition in which one or more of the bones that make up a baby's skull in the head fuse together at the point where the bones meet (sutures) before the usual time, limiting the baby's head growth.

If you're concerned about the shape of your babies head or have any questions about Craniosynostosis, get in touch with your GP or your specialist Steeper Clinic team.

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