

## INSIGHTS

## Family reflections: submucous cleft palate

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Every parent thinks their baby is the most beautiful one in the world and it was no different when Noah was born in 2009, with his slightly squishy chin and big, pale eyes, he seemed perfect. It was only feeding that seemed a bit tricky; he couldn't breastfeed and when we tried bottle feeding, milk just came shooting out of his nose. It was a bit disconcerting and, without fully understanding the cause of the problem, we would place his Moses basket at such an angle for fear of him choking on milk that he would sometimes slide down it and we'd find him all squashed up at the bottom.



We were prescribed reflux medicine which, not surprisingly, didn't fix the milk regurgitation and although he put on weight, nothing would stop him crying. The first year and a half was hard work, but it was only when he missed the 18-month milestone of being able to make a few identifiable sounds that anything became apparent. He was assessed by a speech and language therapist who pointed out a bifid uvula and suggested he might have a cleft palate. She also thought he had severe oral dyspraxia. It was a lot to take in, knowing nothing at the time about dyspraxia and very little about cleft palates, but it also helped make sense of some of the problems we had had.

Communicating was a challenge so we learnt Makaton. We found that where Noah lacked speech, he had excellent non-verbal communication skills. He was very shy though and didn't really socialise the way his older sister had done at the same age.

After a referral to and then subsequent careful assessment by the multi-disciplinary cleft team at St Andrew's Centre at Broomfield Hospital, Chelmsford, a submucous cleft palate was diagnosed, but it became clear that he presented a number of other speech difficulties that were unrelated to his velopharyngeal dysfunction which were consistent with dyspraxia. We were told

that he would need intensive speech therapy to resolve these difficulties after surgery.

I felt a little intimidated meeting the team at St Andrew's for the first time, but it is such a brilliantly organised and professional set-up that we felt we were in good hands. Noah had the first surgery to repair his palate when he was 3 years old. His grandparents bought him some Scooby Doo figures for him to play with after his operation so he always associated our future trips to the hospital with new Scooby Doo toys. It was an expensive time!

As soon as his mouth had healed, we started speech therapy. We were blessed with two wonderful speech therapists we will forever be indebted to. Natalie Pancewicz at St Andrew's helped Noah practice his sounds with his palate in mind. Sarah Colebourne was a private speech therapist we contacted who has a wealth of experience in treating children with dyspraxia. We called Sarah the child whisperer for her amazing skills at keeping Noah happy for over an hour at a time as she patiently taught us both where to position the tongue. We would go home after our weekly session with new cards to practice.

Over the following 2 years, Noah had to learn each letter of the alphabet one by one and we practiced his sounds every single day for half an hour at a time, working our way through every game we could think of. It was sometimes hard keeping it fun and some days, neither of us felt like doing it, especially when we were faced with a particularly problematic letter. Giving up wasn't an option though and those hours we spent playing games brought us closer together. I look back on those precious hours now and I'm glad we had that time to connect.

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The palate repair wasn't enough on its own unfortunately so at 4 years of age, after having a sleep study carried out at Great Ormond Street ('Noah's funny sleepover'), a Hynes pharyngoplasty was carried out. Again, the multi-disciplinary team were excellent and we were very blessed to have cleft surgeon, Mr Kangesu, treat him this second time. In the months following the operation, Noah's speech was still very difficult to understand and his complex speech difficulties were worrying. I didn't ever doubt we would get there, but there were a few more hurdles to climb first.

Noah was due to start school that year but we delayed his start to give him more time to work on his speech. In the meantime, he attended a nursery that had a specialist speech and language unit within it. Noah and four other children with their own complex speech requirements became great friends. It was very heartening to see that speech is just one form of communication and friendships grow in unlikely circumstances without the need for many words.

When he started school after missing the first term of Reception, we had managed to get him a Statement of Education Needs and again, we were fortunate to have the kindest, most dedicated lady, Mrs Saxton, who came into the school for 20 h a week to help him through his lessons. There were other issues we found along the way. Noah had reduced core stability which impacted his balancing skills. Kicking a football was impossible at first. He had reduced strength in his upper limbs which impacted on his handwriting and is still something Noah has problems with. Mrs Saxton and Noah became great friends over the coming years and she undoubtedly helped him grow and develop, getting him to practice on the balance beam until he could kick a football just like the other boys in his class. She stayed with Noah until year 3 when we realised that Noah could manage without her—although he missed her very much afterwards.

One other speech difficulty Noah gained along the way was a stammer, which to this day ebbs and flows, unwelcome and unwanted, depending on stress levels. We tried speech therapy for this—both group therapy and one-to-one treatment but nothing much seemed to help. Noah hates his stammer more than anything, but it is part of who he is now and only sometimes rears its head.

At 8 years old, Noah needed one more operation, this time orthodontic treatment. He had a row of additional teeth overlaying the upper central incisors which had to be removed. A gold chain was glued to the incisors then passed through his gum and attached to a brace to pull down the teeth. It sounds painful but it only really hurt when it had to be tightened every 6 weeks, back at St Andrews. Those teeth did come down eventually but it took 8 months and a lot of visits to the orthodontist.

At 12, Noah is now at Secondary School. He has lovely teeth although he may need a brace to straighten one, very slightly crooked tooth at the front. He can express himself very eloquently and can say every sound beautifully but with a slight lisp. He still stammers occasionally and his gross motor skills are still a little problematic, but he gets through life being easy-going, loyal, kind, affectionate and sensitive to others.

As for me, Noah's mum, I started working for the charity, CLEFT in 2018 (registered charity number 1194581). CLEFT aims to be the UK's leading charity working to prevent cleft lip and palate by funding research into the causes of clefts and training medical professionals to treat children with clefts in lower and middle income countries. CLEFT is working to bridge the gap in cleft care and aims to create sustainable, long-term solutions for local teams so that more children can receive effective treatment.

Not a day goes by that I don't fully appreciate and feel inspired by the value of the multi-disciplinary team here in the UK, working together to treat each child with the kindest surgery possible, and I wish that this approach and the resources we have available to us here could be made available in resource-poor countries.

There is still a lack of certainty about the best techniques for surgical treatment of clefts. At present the results are far from perfect. There is limited research funding available from the NHS and the pharmaceutical industry. Cleft research has not been a priority because it is not seen as life threatening. It is, however, critical to quality of life, so charitable support has been and remains crucial to progressing research to help cleft patients. The research that CLEFT has funded looks at three key areas: to better understand the likely causes of clefts, to find new treatments and to improve the speech of children who have had cleft palates. Better understanding is needed if surgeons, speech therapists and medical professionals are to provide better long-term treatment for people born with clefts.

#### COMPETING INTERESTS

The author declares no competing interests.

#### ADDITIONAL INFORMATION

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