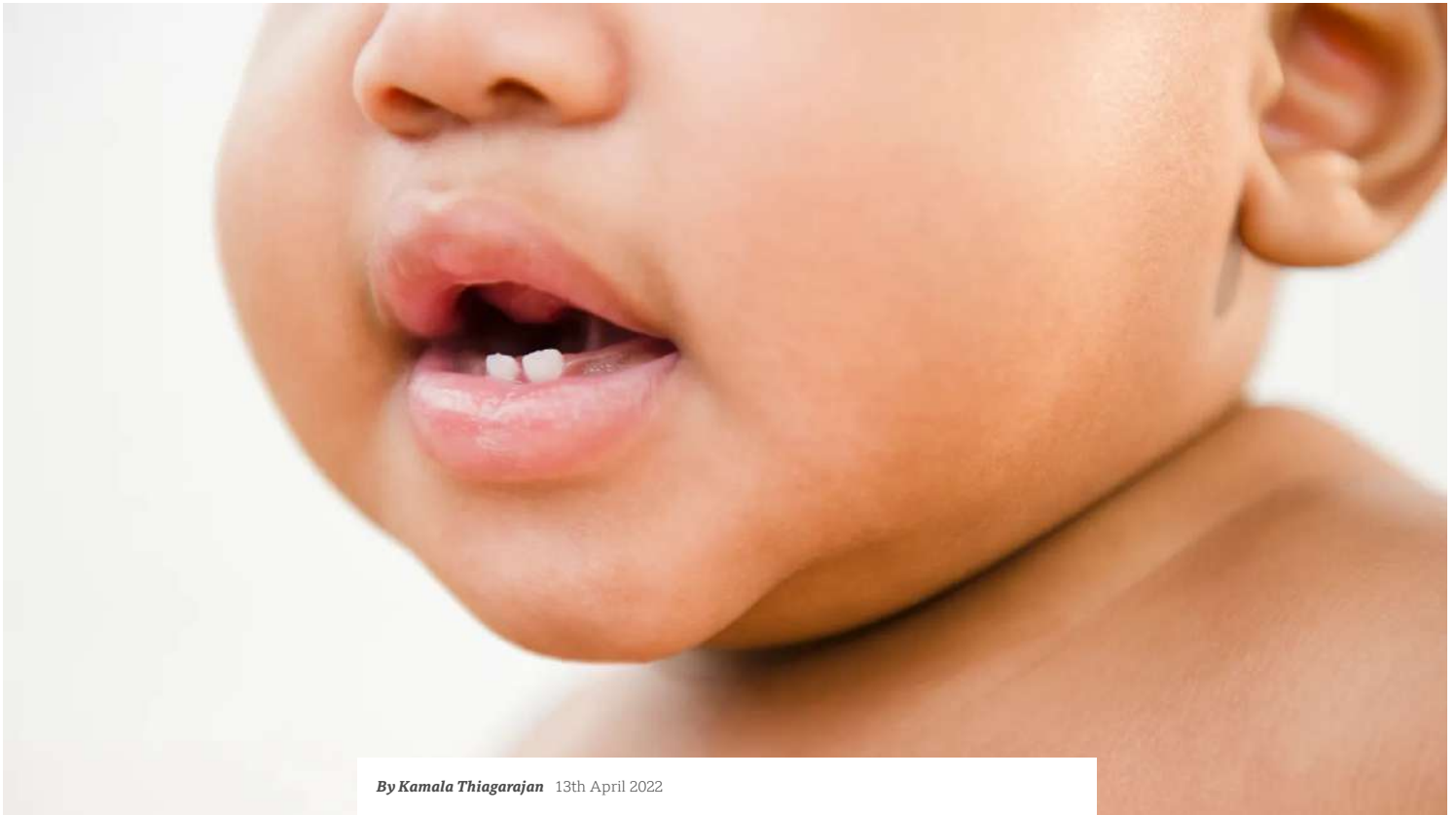


FAMILY TREE | HEALTH

How dangerous is tongue-tie?



(Image credit: Getty Images)



By Kamala Thiagarajan 13th April 2022

Awareness of tongue-tie, and its hidden impact on children's health, is rising around the world. Here's how it can be spotted and fixed.

Purna Parmar had been looking forward to breastfeeding her son, Janav, after his birth in 2011. But whenever he latched on to her breast, she felt a searing pain. Soon, her nipples were sore, raw and bleeding. "I found it excruciatingly painful," says Parmar, a customer care executive in Mumbai, India. "And yet, I was wracked by guilt that I couldn't even do this basic thing for my child."

Everyone around her was dismissive of the problem, suggesting it was natural for new mothers to face some breastfeeding issues. Her pediatrician suggested she switch to formula. Instead, she put up with the pain and kept up with the feeding routine as best as she could. But as time passed, Parmar realised something was wrong. At parties, her son could never play with the other kids, because he was always the last to finish his meal. At home, mealtimes were draining. Janav lingered over his food, taking up to two hours to finish.

"At first, I thought he was a sluggish eater," says Parmar. "Even his walking was slow and unsteady. And he just couldn't balance on a bike." Rushing him only created more stress. Eventually, she pureed his meals, as he couldn't chew and swallow most foods. He was constantly exhausted.

In 2019, when Janav was eight years old, the mystery was finally solved: he was diagnosed with a severe case of ankyloglossia, also known as tongue-tie, a genetic condition now gaining attention from medical experts and families around the world.



The first signs of tongue-tie can be problems during breastfeeding. Later, children may struggle to chew and swallow food (Credit: Getty Images)

In babies born with tongue-tie, the thin strip of tissue that connects the underside of the tongue to the mouth is unusually tight. This means that instead of resting on the roof of the mouth, the tongue is tied to the floor of the mouth, which can prevent the babies from feeding properly.

The condition is thought to be genetic, and has been **known for millennia**, but can be hard to diagnose. In the United States, **about 8% of children under one-year-old** suffer from it, according to a review published in 2020.

In some countries, tongue-tie cases have increased 10-fold

Experts say that awareness of it has been rising around the world in recent years, and some countries have seen a **more than 10-fold increase in diagnosed cases**. In the US, both **the number of tongue-tie diagnoses, and tongue-tie surgeries, have soared**.

However, there are still families like Parmar's suffering through years of pain and stress caused by undiagnosed tongue-tie. In developing countries like India, healthcare providers may focus on fighting more immediate threats to babies' health, such as infections, and as a consequence, leave tongue-tie unnoticed and untreated for years. Even in countries where the condition is more frequently diagnosed, it can be overlooked.

Some years ago, Kate Canavan, a mother-of-two living in Raleigh, North Carolina, noticed her younger daughter Anna's speech was not very clear. Anna was only two years old at the time, Canavan had not had any breastfeeding issues, and her pediatrician told her not to worry about it. It wasn't until Anna was four that another pediatrician said something could be amiss and referred them to a speech therapist.

"The speech therapist told us that she had a lip-and-tongue-tie and if those weren't addressed, the speech therapy really wouldn't be very effective because her mouth anatomy was limiting her articulation," says Canavan, meaning, her daughter couldn't move her lips and tongue freely enough to speak clearly.

Trapped

The first signs of tongue-tie can be problems and pain during breastfeeding, as in the case of Parmar and her baby son.

"Children with tongue-tie can't extend their tongues beyond the tip of their lips. This results in ineffective latching, sucking and swallowing, all actions that are so essential for breastfeeding," says Ju-Lee Oei, a senior neonatologist at the Royal Hospital for Women in Randwick, Australia.

As the baby tries to move the trapped tongue and clamps down on the breast to try and feed, the result can be extremely painful for the mother.

For others, like Canavan's daughter, the problems emerge later.

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Many children enjoy moving their tongue, which helps strengthen it. Tongue-tie can make those activities difficult or even impossible (Credit: Getty Images)

"Many children with tongue-tie will not have symptoms," says Amulya K Saxena, a consultant paediatric surgeon at Chelsea Children's Hospital, Chelsea and Westminster Foundation Trust and president of the European Association of Paediatric Surgeons, in an interview over email.

The tethering of the tongue itself can be hard to spot. The lingual frenulum is a strip of tissue extending from the back of the mouth to the midline of the tongue. If this tissue is restrictive, the tip of the tongue can't extend beyond the lips, the tongue-tie can be quite evident. However, there is a more hidden kind of tongue tie, located deeper in the mouth, which requires a health professional to detect and diagnose, Saxena says.

Children living with tongue-tie may find it hard to use their tongue freely, be it to play a wind instrument, lick their lips or an ice cream, or use their tongue to help clean their teeth during the day. "In some children, it may cause cuts under the tongue if the lingual frenulum gets trapped between the lower incisor teeth," Saxena says.

The tongue's awkward position, and weaker tongue muscle as a result of the lack of movement, can cause problems beyond the mouth.

"One of the biggest issues with tongue-tie is that the air-pressure balance in the mouth is affected, and this can cause nasal breathing that disrupts sleep," says Ankita Shah, a paediatric dentist and director of the Tongue Tie and Sleep Institute in Mumbai, who diagnosed Parmar's son's case.

Children with tongue-tie often contend with open-mouth breathing and snoring, she says, which affects the quality of their sleep. They wake up frequently with a congested nose, and tend to clench or grind their teeth while asleep, leading to neck and shoulder stiffness, and headaches. The constant discomfort, even if quite subtle, can affect their posture and overall wellbeing.

"We don't realise how much the alignment of the teeth, tongue and the jaw can influence an entire range of body functions," says Shah.

A quick fix?

In milder cases, the problem may resolve itself, says Saxena, the London-based surgeon. The connecting strip stretches as the baby feeds and moves her tongue, and over time, the tongue is less restricted. Advice on the right breastfeeding technique, massaging the frenulum, and exercising the tongue can all help resolve such mild cases, in his view. But if that doesn't work, or if the tongue-tie makes breastfeeding very difficult, he recommends the release procedure. This involves a small cut into the frenulum to help release the tongue.

However, all of these problems – struggling with feeding, eating, breathing, sleeping and speaking – can have other causes. And while in countries like India tongue-tie may be under-diagnosed, some doctors in other countries see a risk of over-diagnosing it.

We went from 10 cases of tongue-tie a month, to 10 per week - Ju-Lee Oei

"In 2017, when we had a huge surge in cases, we decided to look into it," says Oei. The Royal Hospital for Women in Randwick, Australia, where she works, records 4,500 births on average each year. Until that year, they usually had only 10 requests for tongue-tie surgery every month. "We went from 10 a month, to 10 cases per week," says Oei.

Cases at other hospitals in the area had risen too, and some practitioners were charging steep rates for the procedure. "We realised that the surgery was in high demand because it was seen as a quick-fix to correct breastfeeding troubles. However, cutting the frenulum to release the tongue doesn't magically solve all problems," she says.

The results of their global study, published in 2018, noted that the diagnosis of tongue-tie had risen more than 10-fold in some countries, **varied considerably around the world** and that greater efforts to standardise care were needed.



For some babies, releasing the tongue can help with breastfeeding. But not all feeding problems are caused by tongue-tie (Credit: Pedro Pardo/AFP/Getty Images)

FAMILY TREE

This article is part of **Family Tree**, a series of features from the BBC that explore the issues and opportunities that parents, children and families face all over the world. You might also be interested in some other stories about babies' health and development:

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Since then, the guidelines at their hospital have changed, says Oei. Every child struggling to breastfeed because of suspected tongue-tie must now be assessed by a breastfeeding consultant. Surgery is recommended only after two-to-four weeks of trying to solve the breastfeeding issues with the consultant's support.

As Oei and her colleagues note in their research paper, even the relatively simple surgery used for tongue-tie should not be carried out lightly, as "subjecting infants to a surgical procedure, no matter how minor, causes pain, stress, possibly longer-term neurological harm".

Surgery and 'tongue yoga'

Saxena, the paediatric surgeon in London, has noticed that families are growing more aware of tongue-tie. "Patient support groups and professional bodies are now offering information on social media," she says.

In India, Shah has also observed a rise in the number of families seeking help, including those with older children. But she, too, advises against resorting to surgery too quickly.

Out of 10 patients who walk into her clinic, roughly only half will need surgery, says Shah. It depends on the severity of the tongue-tie, and its impact on the body,

including the airways. "We evaluate the varying symptoms each patient has with this condition, and we ask ourselves if the problem is only because of the tongue-tie? We try to correct other associated problems first before opting for surgery."

While older children may need general anaesthesia, cases in younger children tend to be treated with local anaesthesia, Shah says. In the case of newborns, anaesthesia isn't used at all, as the risks would outweigh the benefits.

However, surgery is not the end of the treatment, says Carmelle Gentle, an independent midwife and breastfeeding consultant based in London. Gentle, who has set up a donation-based tongue-tie centre in South London, recommends that parents help the baby use and strengthen their tongue after the snip, through various exercises.

"We support babies to use their tongue in a new way," she says. "It's a bit like yoga. You may not be able to touch your toes at the beginning of the session, but regular, gentle practice helps you get there."

I was just so relieved that there was a name for what we were going through – Purna Parmar

For some, the growing awareness – and right diagnosis – can be life-changing.

Kate Canavan's daughter, Anna, was helped by surgery. "Because her frenulum was so thick and muscular, and she was so young, the speech therapist and an [ear, nose and throat specialist] recommended that the procedure be done with a surgical scissors and under general anaesthesia. That way, they would be careful to not damage surrounding tissue while releasing the tongue," says Canavan over email.

After the 15-minute procedure, Anna didn't need any pain medication and was able to eat and drink without any problems. She even went to pre-school the next day. Within a month of surgery, her speech improved dramatically.

Purna Parmar in Mumbai, whose son had suffered from tongue-tie for so many years, burst into tears when her doctor told her about the condition: "I was just so relieved that there was a name for what we were going through."

It then took her two years to convince her family that an operation was necessary, but it was worth it, she says. He had the surgery, and it helped. Today, Janav enjoys experimenting with different foods, can finish his meal in 20 minutes – and is then off to ride his bike.

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