



# Tongue-Tie

## What Everyone Needs to Know

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**A**s a speech pathologist for over 24 years, I have seen many patients with various diagnoses. Since my practice specializes in oral motor and feeding disorders, I meet many patients who have been struggling with speech and feeding issues for some time, often with limited progress. Most concerning is the pediatric referrals, with frantic, sleep deprived parents who are doing everything possible to help their infant stay hydrated and thriving. Too often a simple symptom was missed, a tongue-tie.

Take, for example, my former patient Molly (name has been changed for privacy). Molly's mother emailed my office because her 18-month-old daughter was

still using a bottle, would barely eat pureed foods, gagged and choked on solids and could not drink from a straw or cup. Everyone thought Molly was just being stubborn or picky, but not Molly's mom. After months of concern, the pediatrician gave a referral for a feeding evaluation. As soon as I read the case history forms, I immediately knew that a tongue-tie assessment was needed.

When I got the full story, feeding issues started at birth. Molly's mother was not successful at breastfeeding. She had a great deal of pain and Molly was losing weight. Mom was very disappointed and frustrated as she wanted to breastfeed, but did not want Molly to be under nourished. She had seen a lactation consultant (IBCLC) that

suggested tongue-tie, but the pediatrician did not feel it was an issue. The plan was to pump breast milk and use a bottle. Bottle feedings were not great either. Molly was always "colicky" and spit up often. Reflux medication was prescribed, but it did not really help. It was a constant struggle. Molly did not like pureed foods when introduced and when Gerber Puffs and Cheerios were started, Molly's mom stated that it was like she had no idea what to do with them. They would just sit in her mouth, or she would pocket them like a chipmunk. Eventually Molly would scream and cry at each meal, and PediaSure was her main source of nutrition.

When I assessed Molly, I found that the lactation consultant was right; she clearly

had a tongue-tie, but it was not the type most people are used to seeing. Most people are used to an “anterior” tongue-tie that causes the tongue to be heart shaped and is attached to the tongue tip.

Molly’s issue was different. It was not attached to the tongue tip, but rather it was a short, thick band of fiber located posteriorly, behind the salivary duct. This is known as a posterior tie, and often missed by medical professionals. Why is this happening? It is happening mainly because the training of Tethered Oral Tissues (TOTs) occurs on a post-graduate level and is sought by the professional voluntarily. Dr. Anthony Jahn, a well-respected New Jersey/New York City-based otolaryngologist claims, “You can’t see what you don’t know,” and this is very true of TOTs.

Molly came for pre-operative sessions so help prepare her for a frenectomy, and then came for therapy for 6 months after the surgery. She learned to eat purees, solids and drink through a straw and cup. She is now a happy and thriving preschooler who eats a variety of foods and no longer has reflux symptoms. A seemingly simple problem was clearly overlooked, and this happens too often in my practice.

### **What Is A Tongue-Tie?**

Most people use the term “tongue-tied” when they do not know what to say, but tongue-tie is an actual medical diagnosis that can impact the way people eat and/or speak. Ankyloglossia is the medical term for a tongue-tie. It is a restriction of the frenulum located under

the tongue. A frenulum is supposed to be like a stretchy band that helps the tongue’s movement, but sometimes people are born with an abnormal or restricted frenulum. The lingual frenulum is one of seven frena in the mouth. Four buccal frena (upper and lower), two labial frena (upper and lower) and one lingual frenulum exist, and any one of them can be “tied” or restricted. This is called Tethered Oral Tissue or TOTs. Lip-tie is often corrected when a person has a gap between the two front teeth.

### **How Does Tongue-Tie or TOTs Cause Problems?**

So, what are the symptoms? In infancy, the first sign is breastfeeding difficulty such as maternal pain and failure to thrive (gain weight). This, however, is only one issue that can be impacted by TOTs as symptoms can cross the life span. As babies grow, they may seem to have picky eating habits, just like Molly. They may also seem to have developmental speech problems, like a lisp, but the root of the problem is structural.

TOTs does not just impact babies and young children. I see patients in my office across the lifespan. Signs and symptoms of TOTs also include: reflux/aero digestive issues, orthodontic issues, sleep apnea and TMJ. TOTs may cause tightness of the head and neck, which results in pain and discomfort. The red flags of TOTs are: feeding difficulties; speech clarity issues; orthodontic problems; chronic jaw, head or neck pain; and reflux.





### How Is TOTs Treated?

For many years, it was commonplace for newborns to have the tongue-tie “clipped” before being discharged from the hospital. Doctors thought it helped with breastfeeding. This procedure is known as a frenectomy, which Molly eventually had as a part of her care. Unfortunately, tongue-tie was also mistakenly clipped, for individuals who stuttered or had speech delays. Perhaps the procedure was done too freely. Then, with the formula feeding surge in the 70s, the surgery rate dropped and the baby

was thrown out with the bath water, leading to tongue-tie surgery being somewhat of a taboo.

Now that the World Health Organization (WHO) supports breastfeeding based on important research, tongue-tie is a hot topic, and there is controversy on when to perform the surgery and how. TOTs is not a condition that all medical professionals are trained in, so the surge of frenectomies may seem to be a fad to some, TOTs expert Dr. Bobby Ghaheer argues that it is more likely due to increased awareness and genetics that have TOTs identification on the rise.

### Finding Help

TOTS treatment can be complex as there are many professionals who make up a TOTs team. In the tristate area, parent advocate Krysten Glor created the New York and New Jersey Tongue-Tie Group on Facebook to help parents find the right providers. TOTs care involves a team of professionals that provide pre- and post-operative interventions, such as: chiropractors; international board certified lactation consultants; occupational and/or physical therapists; registered dental hygienists; speech-language pathologists; and surgeons.

If you suspect that you or your child has TOTs, the first step is speaking to your

physician. There are many organizations that can help with a referral to a highly trained provider and/or therapist, including Ankyloglossia Bodyworkers; International Association of Orofacial Myology; International Consortium for Ankylofrenula Professionals; International Association of Tongue-tie Professionals; and TalkTools.

Patients should schedule their functional assessment prior to any surgical procedure and have their therapist of choice on deck to assist with aftercare.



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