TOTs Basics by Merkel-Walsh and Overland

WHAT ARE FRENA?

There are seven oral frena : 4 buccal, 2 labial and 1 lingual.

Here are some frena facts:

- Frena are fibro-mucosal folds of tissue that connect bone to soft tissue and support or limit movement.
- Frena are fully developed by 4-8 weeks in utero and quickly dissociate from the connecting structure like a zipper. By 18 weeks there is 25% dissociation and there should be full detachment by birth. When this dissociation does not occur the frena may become tethered which means "*to tie with a rope or chain so as to restrict its movement."*
- Martinelli, Marchesan, Gusmao, Rodrigues & Berratin-Felix (2014) taught us that frena are **"collagen fibers that cannot be stretched".**
- Mills, Pransky, Geddes & Mirjalil (2019)'s research revealed that the frena are **"dynamic three-dimensional structures that varies in morphology on a spectrum and that it is created by sheets of fascia".** Fascia is a thin casing of connective tissue that surrounds and holds every organ, blood vessel, bone, nerve fiber and muscle in place. The fascia sits between the glands/ducts and the oral mucosa (Lopez & Merkel - Walsh 2022).

WHAT ARE TOTs?

TOTs (Tethered Oral Tissues),is a term was coined by Kimberly Benkert, RDH, BSDH, MPH, COM®, FAADH, which later became a common term when Kevin Boyd, MS, DDS used the term at the International Association of Tongue Tie Professionals (IATP) at their annual conference in Quebec, Montreal Canada in October of 2014. TOTs is defined by Merkel-Walsh and Overland as **"a congenital remnant(s) of tissue that may restrict movement and cause functional impact across the lifespan. TOTs are either too short, too tight, too thick and/or in an atypical location."**

Most list TOTs at about a 3-10% incidence but according to a study by Roberta Lopes de Castro Martinelli, Irene Queiroz Marchesan and Giédre Berretin-Felix (2018), when a proper posterior tongue tie maneuver was used, 32.54% of infants were found to have a tongue tie. More research is required on an international level to determine incidence and prevalence , but until all hospitals and birth centers are professionally trained to screen for TOTs this may be challenging. Brazil has a law in which all infants must be screened for TOTs before discharge.

TOTs may be identified at any stage of life when structure and /or function are impacted. It may be identified at birth by the pediatrician, or noted later in life as feeding problems develop, or in a school setting when a student is identified with speech concerns.

Here are times when we might suspect TOTs:

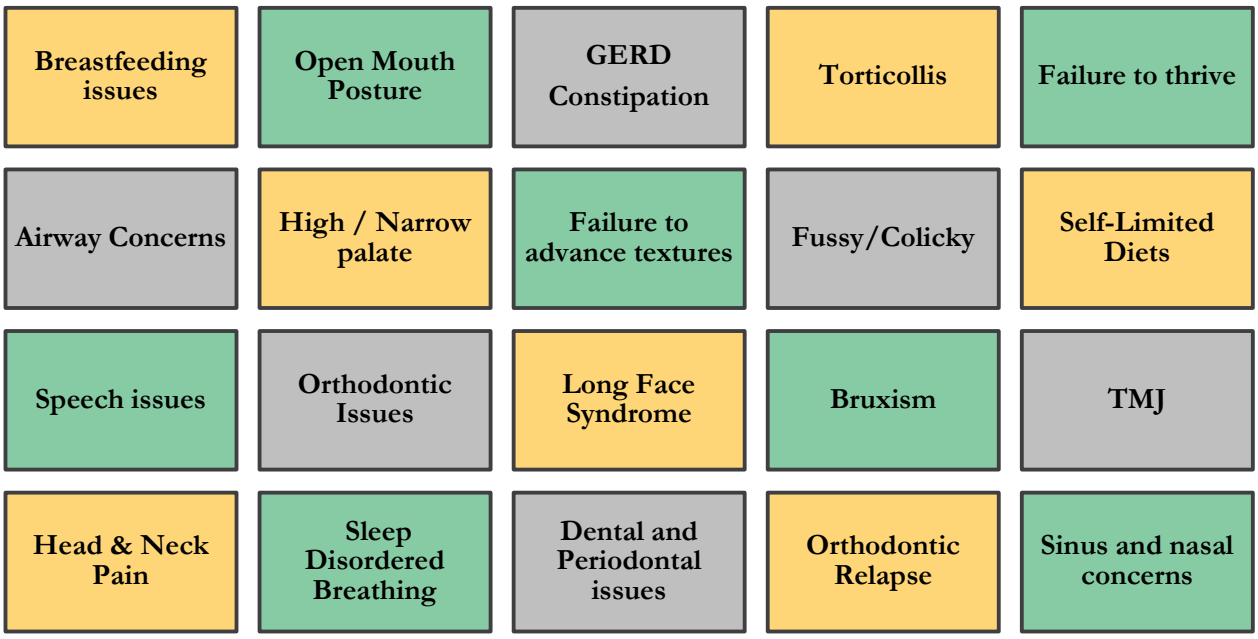
- During feeding challenges across the lifespan
- When medical issues such as GERD and/or Sleep Disordered Breathing are present
- As speech sounds and language develop in babies and children
- When speech deteriorates in the aging population
- During orthodontic treatment and relapse
- When assessing with individuals who have special needs, prematurity, or have a genetic syndrome
- When oral habits do not resolve (ex. pacifier use) or new oral habits such as bruxism develop

The structural red flags of TOTs are (but not limited to):

- Asymmetry of the orofacial complex
- Blanching of the surrounding soft tissue
- Coating on the tongue
- Concave facial profile
- Dental cavities
- Dental inversion
- Dental malocclusion
- Diastema between the two upper or lower incisors
- Dry/chapped lips
- Excessive rugae
- Periodontal disease
- Heart shaped tongue tip
- High and/or narrow palate
- High nasolabial angle
- Labial blisters

- Long face syndrome
- Open mouthed posture
- Overcrowding of teeth
- Recessed mandible
- Upper lip insufficiency

The cumulative and functional red flags of TOTs over time are:



TOTs MISCONCEPTIONS

Unfortunately, not all professionals are trained in TOTs even though it can impact multiple systems of the body. One must understand that TOTs is not only a congenital anomaly, but an **Orofacial Myofunctional Disorders (OMD)** https://talktools.com/pages/omt-orofacial-myofunctionaltherapy101. Quite often, only those who sought specific training in OMDs recognize the signs and symptoms of TOTs. Others may contest their findings.

Here are some TOTs misconceptions and facts:

Misconception: TOTs is a fad and too many surgeries are being done.

FACT! The increased identification of TOTs according to Dr. Ghaheri is due to 1) increased breastfeeding; 2) increased professional training and 3) increased public awareness.

Misconception: If you can stick your tongue out you are not tongue-tied.

FACT! There are variegated movements of the tongue for oral rest , feeding and speech. These include protrusion, retraction, lateralization , elevation, and back tongue side spread. Tongue protrusion is for the /th/ sound, licking an ice cream cone and French kissing. Tongue retraction is required for all speech sounds (but /th/) , feeding and swallowing, Lateralization is needed for chewing, cleaning foods from your molar teeth, moving food across the midline and is a pre-requisite to elevation. Elevation is required for speech and swallowing and proper resting posture. Back tongue side spread is needed for sounds such as /sh/ and /r/ and assists with tongue to palate for resting posture and swallowing. All tongue functions should be assessed before deciding if the tongue is restricting movement.

Misconception: Lip ties do not impact speech or feeding.

FACT! The lips participate in breast feeding, bottle feeding, cup drinking, straw drinking, masticating and should be closed at rest. The lips help produce speech sounds such as /m/, /o/ and /r/. If the upper or lower lip is tight, incompetent, or restricted, any level of feeding or speech could be impacted.

Misconception: Even If the child is tongue-tied, they can learn to compensate.

FACT! When a person repetitively and routinely compensates for TOTs, it often involves abnormal jaw tensing, atypical oral resting posture, tongue thrusting, atypical head and neck posture, mouth breathing, atypical speech/articulation placements and can result in dental malocclusion, gum disease, speech, and swallowing issues. It can even be correlated with pain and tension in the neck, back and whole body. TOTs is **"ticking over time,"** (Merkel-Walsh, 2020) with some conditions that get worse over the years , such as sleep disordered breathing or TMJ. Also, to note since frena have fascia, and fascia are connected to nerves which are sensitive, one could imagine that the tethering of these tissues could cause some level of pain if stretched or pulled beyond its' range.

Misconception: Do not worry about a lip tie because the child will tear it at some point in a fall or accident.

FACT! This common statement is genuinely concerning. If an adult male had a growth on his skin, would you hope for it to be torn off while shaving? Tearing a frenulum does not release it and correct function, in fact it may be torn asymmetrically and/or scar down causing more complications.

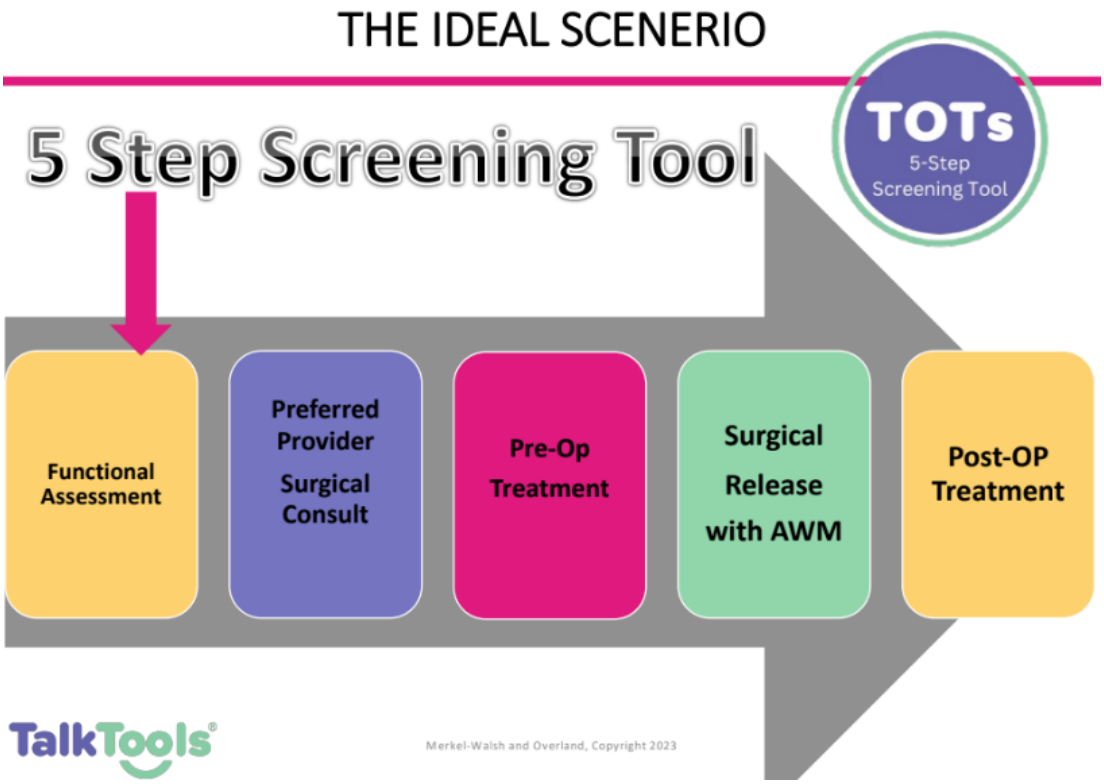
Misconception: There is NO research to support that tongue tie impacts sleep, feeding or speech. The evidence is lacking, or the studies are of inadequate quality.

FACT! Evidence Based Practices (EBP) are intrinsic and extrinsic. EBP includes well-designed studies, patient values and preferences, and a clinician's expertise in making decisions about a patient's care. Merkel-Walsh & Overland have created a 14+ page reference list that is updated each month found at https://talktools.com/pages/tots-tethered-oral-tissues.

Since 2014 there has been a surge in TOTs research. Some examples are ultrasound studies that found improvements in breastfeeding post frenectomy (Genna, Saperstein, Siegel, Laine & Elad, 2021) and cohort studies on parent perspectives of functional improvements in speech and feeding post frenectomy (Baxter, Merkel-Walsh, Baxter, Lashley & Rendell, 2020). Researchers have worked to standardize assessments by looking at lingual frenulum length and mobility (Yoon, Zaghi, Weitzman, Ha, Law, Guilleminault & Liu,2017). There are also varying articles and papers internationally on this topic, mostly in the fields of dentistry and otolaryngology.

HOW ARE TOTs TREATED?

The remediation of TOTs is a multifaceted process that is not just about a “snip.” The first step in treatment are proper structural and functional assessments which must consider multiple systems in the orofacial complex and whole body. Ideally, functional impact of TOTs would always be assessed first because it determines medical necessity for a release procedure (frenectomy/frenuloplasty/frenotomy). Merkel-Walsh & Overland (2019) developed the 5-Step Screening Tool to promote pre-operative functional assessments and care:



Pre-operative care should start as soon as possible . It has three goals:

Pre-op Goals

Client

- to acclimate to therapy, maximize range of motion and release fascial tension for a more optimal release.

Caregiver(s)

- to receive training on neuromuscular re-education protocols that are critical to optimal release.

Clinician

- to establish ongoing baselines and data collection to further assess pre-op limitations and set forth an individualized plan of care for optimal release.

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Post-operative therapy has two stages of care.

Post-op Goals

Active Wound Management

- Maintain the integrity of the wound
- Avoid scarring and re -attachment
- Directives from the surgeon

Neuromuscular Re-education

- Remediate functional challenges that are impacting pre -feeding, feeding and speech

4

The surgeon who performs the release often scripts “aftercare” or “stretches” or “wound management.” The terms are often synonymous; however, this is different from goal based therapeutic care that targets functional skills. Too often we see the intervention stopping after the wound care phase is completed which averages 3 weeks. Surgery alone is not always enough to improve function. The tissue will continue to heal, and fascia and collagen will grow for at least six months post-operatively as a part of the healing process (Jahn, 2020); therefore, the remediation process does not end at wound care.

Neuromuscular re-education is the stage in which a task analysis of functional skills are targeted. Oral motor exercises, pre-feeding goals, feeding goals, speech goals, orofacial myofunctional goals (rest posture, thumb sucking, nasal breathing) etc. are implemented. The techniques will vary based on the cognitive status and age of the patient.

- Infants , babies, and toddlers need more passive techniques such as **pre-feeding and feeding therapy.** We modify utensils, use myofascial release, Beckman Oral Motor Protocol https://www.beckmanoralmotor.com/index.php and massage to map oral sensory motor skills to facilitate improved oral posture, oral motor, pre-feeding, feeding and motor planning.

- In children between 2-4 and up, we continue pre-feeding and feeding methodology, but also start to combine passive with more active therapies such as **Oral Placement Therapy (OPT)** https://talktools.com/pages/opt-oral-placement-therapy which uses specialized tools, such as Bite Blocks, horns, and straws to target speech and feeding goals. We use food and fun motivators as well.

- In four and up we can still use the prior methods , but we can also use **orofacial myofunctional therapy or “MYO”** https://talktools.com/pages/omt-orofacial-myofunctionaltherapy101 and teach the children and older patients the goals as they actively engage and self-monitor lingual resting posture, nasal breathing and more. This therapy is volitional in nature which makes it challenging for babies, young toddlers, and children with special needs.

- The above can be further defined here https://ijom.iaom.com/journal/vol46/iss1/3/ by Merkel-Walsh in 2020.

TOTs TEAM CHEAT SHEET

There are many professionals on the TOTs team. The therapies received should be based on the functional issues noted during assessment. For example, torticollis needs to be treated by occupational and/or physical therapists (OT/PT) while mastication (chewing) weakness should be treated by a speech-language pathologist (SLP) or occupational therapist (OT) who has specialized training in feeding. Adult patients who are snoring and/or have TMJ and head/neck

pain may need a 1) **Certified Orofacial Myologist®** https://www.iaom.com/certification/ who may be an SLP or a registered dental hygienist (RDH), in addition to 2) a chiropractor or PT for the pain management and 3) a sleep specialist / otolaryngologist for airway concerns.

There is often confusion regarding who a patient should see first. It can be time consuming and expensive to care for TOTs; therefore, it is important to understand who is on the team and what the perspective roles could be. A team model is critical and there are various scenarios based on the symptoms. Team members should be well trained and knowledgeable of the various professionals and establish a timeline and hierarchy of patient care for optimal outcomes.

Team members have various aspects of TOTs care in their **scopes of practice** https://cdn.shopify.com/s/files/1/1545/7007/files/FINALLSCOPE4.pdf?452. Some examples are as follows:

Speech-Language Pathologist (SLP or SLP/COM®)	International Board Certified Lactation Consultant (IBCLC)	Occupational Therapist (OT)
• feeding across the lifespan • swallowing • articulation • orofacial myofunctional therapy • Nuerodevelopmental Treatment • oral sensory-motor therapy • oral placement therapy	• treating challenges of the mother infant dyad • breastfeeding • suck training • transitioning from breast to bottle • advising when it is time to start solids • educating on suppemental breastfeeding systems • providing supports such as nipple shields	• feeding across lifespan • oral motor therapy • sensory intergration therapy • CranioSacral Therapy (CST) • wound management • Nuerodevelopmental Treatment (NDT) • Torticollis • improving posture and alignment

Physical Therapist (PT)	Registered Dental Hygeniest (RDH or RDH/COM®)	Bodyworkers (Chiropracter, Osteopath, etc.)
• TMJ issues • head and neck pain • Torticollis • sensory intergration • CranioSacral Therapy (CST) • wound management • Nuerodevelopmental Treatment (NDT) • improving posture and alignment	• wound management • orofacial myofunctional assessment/therapy • early dental screenings 0-3 • oral health education and treatment • assistance with orthodontic appliances	• pain management • reducing fascial tension • improving posture and alignment • massage therapy • overall health and well being

NOTE: COM® = Certified Orofacial Myologist® is a trademarked certification in orofacial myofunctional therapy by the **International Association of Orofacial Myology** www.iaom.com. It encompasses intensive training, written and clinical exams, mentorship, and additional requirements. In addition, COM®s, must maintain approved continuing education in approved coursework in orofacial myofunctional disorders to maintain this certification.

TOTs RELEASE PROVIDERS

In the TOTs community, the surgeon who performs the release is often called the "provider." Both the International Association of Tongue-Tie Professionals and The International Consortium of Ankyloglossia Professionals have data bases of preferred surgeons (and therapists/bodyworkers).

(https://tonguetieprofessionals.org/directory/ ; https://www.icapprofessionals.com/professional-directory)

Many ask about lasers vs. scissors and most experienced surgeons and therapists/bodyworkers will agree that it is the skill of the surgeon that is most important. Some patients do well with laser release wound management, and others may need stitches to reduce the need for aftercare. Some patients can tolerate local anesthetic where some more complex cases may require sedation. These issues must be discussed with the provider. The type of procedure changes the aftercare protocol; therefore, therapists and bodyworkers must be well-trained in understanding various procedures, surgical techniques, and wound healing. For example, an open wound will require more intense wound care in comparison to a wound which is closed with stitches.

Some of the most well-known and skilled providers in the USA are:

Dr. Richard Baxter, Alabama https://tonguetieal.com/

Dr. Bobby Ghaheri, Oregon https://www.drghaheri.com/

Dr. Lawrence Kotlow, New York https://www.kiddsteeth.com/

Dr. Scott Siegel, New York https://www.drscottsiegel.com/

Dr. Soroush Zaghi, California https://www.thebreatheinstitute.com/

TOTs TAKEAWAYS

Merkel-Walsh and Overland's text *Functional Assessment and Remediation of Tethered Oral Tissues* and coordinated courses are comprehensive but there are few facts they feel are important to share :

1. Breastfeeding dyads should always see an IBCLC. If there are significant oral motor and feeding issues or suspected swallowing issues (dysphagia) the patient may also need to see a licensed SLP or OT. Some SLPs/OTs are dually certified as lactation counselors, specialists or IBCLCs. Many professionals cross refer based on the patient's needs.

2. Oral-motor disorders and /or orofacial myofunctional disorders require oral motor and/or myofunctional therapy. Bodywork is important when required but does not replace the direct work on oral motor and placement skills that are needed for feeding and speech. Only a licensed speech and language pathologist can treat speech disorders.

3. The age and cognitive status of the patient drives the treatment modalities . Passive vs. active. Oral motor/feeding vs. myofunctional. (Merkel –Walsh, 2020).

4. Certain treatment modalities are covered by insurance when delivered by a licensed professional and others treatment methods may not be. It is always best to check with your carrier what will be covered, find out about the provider credentials, and ask in advance for procedure and diagnostic codes to be aware of out-of-pocket costs prior to intervention.

TEXTS on TOTs:

Baxter, R. (2018). Tongue Tied: *How a tiny string under the tongue impacts nursing, speech, feeding, and more*. Alabama, GA: Alabama Tongue-Tie Center.

Boshart, C. (2015). *Demystifying tongue tie, methods to confidently analyze and treat a tethered tongue*. Ellijay, GA: Speech Dynamics Inc.

Kotlow, L. (2016). *SOS for TOTS*. Troy, NY: The Troy Book Makers.

Merkel-Walsh, R. & Overland, L. (2018). *The functional assessment and remediation of tethered oral tissues*. Charleston, SC: TalkTools®.

Zimmerman-Pine, P. (2018). *Please release me : the tethered oral tissue (TOT) puzzle* 2nd ed. Phoenix, AZ: MiniBuk.

ABOUT THE AUTHORS:

Robyn Merkel-Walsh MA, CCC-SLP/COM® and Lori Overland, MS, CCC-SLP, C/DT, CLC, FOM are both licensed speech pathologists who are consultants for TalkTools®. They both have their own practices in NJ and CT, respectively. Robyn can be reached at www.robynmerkelwalsh.com and Lori at www.alphabetsouptherapy.com.