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TOTs 101 for Parents

Easing the anxiety

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Why did I write this?

SLP/COM® here. I've been both a silent and active observer and participant in parent TOTs groups on social media..... because I want to help parents and their children get proper care. I also want to educate the general public. Parents come and go in these groups as their children are released and progress, but the professionals can see the patterns of parental concerns that seem to resonate over and over again.

I see recurring questions from parents in the groups regarding provider referrals for surgeons and contemplating a release, but they haven't had any assessment of function. Many posts have professionals like me jumping in and asking about function and recommending an evaluation. **Parents should understand that a functional assessment is critical prior to the frenectomy.** Releases shouldn't be performed due to appearance alone, but rather due to functional impact. Parents are confused by acronyms and multiple referrals. I understand why in reading the conflicting advice and opinions posted.

Many of my patients come to me with what I call "google-itis" because they've completely freaked themselves out trying to figure out

what to do online. There almost becomes a point of contention when my assessment and advice doesn't line up with what another parent posted. This is problematic because what was needed for one child isn't what's right for another. **Everyone's journey is unique.**

In an effort to help more people at one time, I decided to post some information based on the recurring questions I have read and have answered individually.

Navigating TOTs

Acronyms and Who's Who?

In an effort to help more people at one time, I decided to share some information based on the recurring questions I have read and have answered individually. Here are some general guidelines I hope will help:

1) If breastfeeding is the issue an Independent Board Certified Lactation Consultant (IBCLC) is the "gold standard" and the best professional to consult for the mother and baby dyad. An IBCLC (buccal/lip/tongue tie) can help with a variety of goals including but not limited to: latch, oral motor skills, milk supply, body positioning, maternal pain, feeding progression, caloric volume, safety, weaning and overall optimal health as it relates to breastfeeding. www.ibclic.org can provide more information.

2) Speech and language pathologists (SLPs) are certified and licensed professionals who are excellent for feeding, oral function and speech across the lifespan.

The American Speech –Language and Hearing Association (www.asha.org) has a practice portal specifically listing ankyloglossia (tongue-tie) as a part of orofacial complications that an SLP can assess and treat. Just because one SLP missed your child's tie doesn't mean all aren't trained in this condition. Many of us who do this work with TOTs can help with breast, bottle, spoon, solid, cup, straw, oral aversion, picky eating and speech. We can help you navigate a release provider referral or any other consults you may need. Many times we work with other professionals to assist navigating the stages of feeding.

3) A bodyworker is a professional who has a hands-on license to touch and extensive continuing education hours in CranioSacral therapy, Myofascial release, etc. TOTs trained bodyworkers such as occupational therapists (OTs), physical therapists (PTs) and chiropractors can assist with how the tongue tie can impact fascial tension around muscles and posture / alignment in the whole body. For example, many tongue tied babies have torticollis and need bodywork. OTs/ PTs that are TOTs savvy know how to position the baby / child for feeding and/or use CranioSacral therapy to help support the work of lactation and speech. TummyTime® for example is important for babies with TOTs and TOTs savvy chiropractors really understand how everything in the body is connected and how the tongue can cause issues. Bodyworkers also work on natural pain management (massage for example) and are essential in both pre and post-op goals. OTs are also trained oral motor dysfunction. Like SLPs, it's more of a specialty area, so parents shouldn't assume all OTs (or SLPs) are well versed in TOTs. www.ankyloglossiabodyworkers.com is a helpful resource.

4) A big problem online is confusion about an "Oral Myofunctional Therapist". This isn't an actual

profession but rather a type of treatment. Registered dental hygienists (RDH) and speech pathologists (SLPs) can become certified in orofacial myology. That's what "COM®" stands for. There is no licensure for an "OMT" specifically but rather orofacial myofunctional therapy is a treatment modality that falls under the scope of practice of a licensed professional. To date the International Association of Orofacial Myology (IAOM) is the only non-profit certifying association with a board of examiners, board of directors and vigilant process that involves both written and clinical examinations, along with continuing education requirements to maintain the COM®.

This type of therapy is for age 4 and up when children can consciously engage in exercises and practice oral motor skills and swallowing. It also helps with thumb sucking and other oral habits. We implement strategies, like teaching where the tongue needs to rest on the palate or how to trap water and swallow with the tongue up. We work on developing muscles and correcting compensatory patterns like a tongue thrust that often is caused by TOTs.

Release providers often tell parents of babies and toddlers (0-4) to see an "OMT" but this age group needs oral motor and feeding therapy. Patients in the 0-4 range need an IBCLC, OT or SLP to do feeding and / or speech not an "OMT". So when I see a post "I need an OMT for my 3 week old baby" I worry this may lead to the wrong referral source. While oral motor / feeding and OMT overlap, it's important to understand that only licensed professionals should be doing this therapy and each modality is a different training for the therapist. A COM® may not have infant feeding training and a feeding specialist may not have OMT training. Many aspects of OT/PT overlap with OMT as well because it's all a focus on muscle and motor function. If the child is

above 4 an SLP or RDH can assist with myofunctional problems, but only SLPs treat speech.

Parents should always make sure your therapists / bodyworkers are licensed and question their TOTs experience and training. Many online support groups and websites like the International Consortium of Tongue-Tie Professionals (ICAP) and The International Association of Orofacial Myology can provide referrals.

Why Pre-op Care?

Many parents in social media groups post concerns after a release that the child's reaction to the stretches and aftercare is challenging. Pre-op care alleviates this.

I find myself answering questions about pre-op care daily. In an ideal world no provider would release a tie without pre-op care. Every TOTs savvy therapist and consultant I know discusses this amongst us. Realistically.....it's not always possible due to time, insurance, weight gain issues in babies, availability of the therapists and so forth....but in a perfect world function would always come first. So when parents state "well my pediatrician said he could stick out his tongue so he's not tied". That's because they aren't assessing function. That is the job of the aforementioned professionals.

There are several important reasons for pre op care: 1) pre op assessment of FUNCTION helps determine if a release is needed. 2) Baseline of skills is recorded so that the parent, release provider and therapist(s) can assess progress or lack thereof after the release. 3) Pre op care helps release fascia in order to optimize the release. 4) It is much easier to teach a parent and child stretches and activities they need to

The Three C's of Pre-OP Care

Client

Goal: to acclimate to the input needed for post-op neuromuscular re-education and release fascial restrictions to optimize the release.

Caregiver

Goal: to train the parents and family to deliver the post-op care in a calm and supportive manner.

Clinician

Goal: to establish baselines and establish rapport.

Examples: with a baby the therapist will manually lift the tongue but with a 4 year old we teach the tongue position via stimulation then imitation. That's the difference with oral motor vs. orofacial myofunctional therapies. Same goals apply, but different techniques are used based on the age and cognition of the patient.

Summary

In summary, we have some excellent release providers, therapists, IBCLCs and bodyworkers available to patients. We do our best to assist parents navigate this complex diagnosis and understand that parents can't always see every specialist. Many of the pre and post-op work overlap, but sometimes one cannot replace another. We have to decide what the priorities are for each patient and work as a TOTs team!

do when everyone is calm and there's no discomfort of the patient. 5) Pre-op helps the child get used to intraoral stimuli so after the release they are not aversive and 6) A therapist is lined up for post-op care that your child is familiar with.

Post- op care is important to 1) avoid reattachment and 2) prevent scarring. Post -op laser therapy has two phases 1) aftercare / stretches and 2) neuromuscular re - education (best known in parent terms as "exercises" or "therapy"). This is when the functional progress can begin with muscle-based training. Stretches that the surgeon's offices give to parents are NOT therapeutic interventions. Scissor releases are a bit different because the reattachment issues are less of a concern if stitches are used to help control the healing, but never the less the functional therapy is important in laser or scissor releases. Each patient is different and therapy must be driven by the functional goals AND the type of release.

Post-op Care

Therapists are often referred patients after the release. Understand in these cases we have no baseline of what the child's function was like before the release. Not ideal. TOTs savvy specialists are not common so we are booked solid. It is stressful for parents to try and schedule with the right provider who has a 4+ week wait or no openings at all. We of course feel guilty when we can't get the patient scheduled. Providers should also make sure the patient has this set up before a release (again perfect world!) The release providers are also faced with issues finding TOTs savvy therapists so this can be problematic.

In most cases function doesn't just miraculously self-correct from surgery. The surgery is one piece of the TOTs puzzle. If a motor skill such as feeding or speaking is impaired that motor skill needs to be broken down and carefully re-organized and remediated. Babies receive passive care and older children/adults receive active care.



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Resources

<https://talktools.com/pages/tots-tethered-oral-tissues>www.iaom.com

www.ankyloglossiabodyworkers.com

www.icaprofessionals.com

www.robynmerkelwalsh.com

www.ibcle.org

www.asha.org

www.aota.org

www.apta.org

www.acatoday.org

www.aomtinfo.org

References

A comprehensive list of information on Tethered Oral Tissue by Robyn Merkel-Walsh and Lori Overland can be found at:

<https://cdn.shopify.com/s/files/1/1545/7007/files/TOTSreferences-Sept2019.pdf?422>



