TOTs 101 for Parents

Revised: March 15, 2023
Original: September 2019

Table of Contents

1 Why this newsletter

1 Information on navigating TOTs

1 Understanding acronyms and who is who

2 Why pre-op care?

3 Post-op care

3 Summary

4 Resources

Robyn Merkel-Walsh
480 Bergen Blvd.
Ridgefield, NJ 07657
Robynslp95@aol.com

Easing the anxiety

*Robyn Merkel-Walsh MA, CCC-SLP/COM®, **TalkTools®***

Why did I write this?

SLP/COM® here. I have 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 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 have not had any assessment of function. Many posts have professionals like me jumping in, asking about function, and recommending an evaluation. **Parents should understand that a functional assessment is critical prior to the frenectomy.** Releases should not be performed due to appearance alone, but rather due to functional impact. Parents are confused by acronyms and multiple referrals. I can 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 have completely freaked themselves out trying to figure out what to do online. There almost becomes a point of contention when my assessment and advice does not line up with what another parent posted. This is problematic because what was needed for one child is not what is right for another. **Everyone's journey is unique.**

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:

Navigating TOTs

Acronyms and Who's Who?

Let us chat about who can assist with your child's care.

1) If breastfeeding is the issue an International Board-Certified Lactation Consultant (IBCLC) is the "gold standard" and the best professional to consult for the mother and baby dyad. An IBCLC can help with a variety of goals including but not limited to latch, suck training, milk supply, supports, positioning, maternal pain, feeding progression, caloric volume, safety, weaning and overall optimal health as it relates to breastfeeding. www.iblce.org can provide more information.

2) Speech and language pathologists (SLPs) are certified and licensed professionals who may seek training in feeding, oral function, and speech impacted by TOTs. 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 does not mean all are not trained in this condition. Many of us who do this work with TOTs (buccal, labial, and lingual ties) 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, SLPs collaborate 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® (Emanuele, 2018) 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 in oral motor dysfunction. Like SLPs, it is more of a specialty area, so parents should not assume all OTs (or SLPs) are well versed in TOTs.

4) There is confusion in some parent groups about finding an “Oral Myofunctional Therapist.” This is not an actual profession but rather a type of treatment. Registered dental hygienists (RDH) and speech pathologists (SLPs) can become certified in orofacial myology. That is what "COM®" stands for. There is no licensure for an “OMT” specifically but 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. The therapist implements 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 provide oral motor and feeding and / or speech therapy 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 is 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 is 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 Oral Ankylofrenula Professionals (ICAP) and The International Association of Orofacial Myology (IAOM) can provide referrals.

Why Pre-op Care?

Many parents in social media groups post concerns after a release that the child's reaction to “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 regularly. Realistically, it is 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 is because they are not assessing function. That is the job of the therapists previously mentioned.

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 to optimize the release. 4) It is much easier to teach a parent and child stretches and activities they need to do when everyone is calm and there

Merkel-Walsh & Overland's "3-Cs" of Pre-Op Care

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

Caregiver
Goal: to receive training on neuromuscular (functional therapy) re-education protocols that are critical to optimal release.

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

is 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. *(This is critical do not wait until after to call for help).*

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 cannot 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.

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 nevertheless 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.

In most cases function does not 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. 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 is 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 excellent release providers, therapists (SLP/OT/PT), RDHs, IBCLCs and bodyworkers available to patients. We do our best to assist parents navigate this complex diagnosis and understand that parents cannot always see every specialist. Many of the pre- and post-op therapies may overlap, but sometimes one cannot replace another. Oral motor issues require oral motor interventions first. We must decide what the priorities are for each patient and work as a TOTs team!

Robyn Merkel-Walsh is a speech pathologist and Certified Orofacial Myologist® with over 27 years' experience as a clinician, author, and lecturer. Robyn can be reached at robynslp95@aol.com.

Resources

www.iaom.com

www.icapprofessionals.com

www.robynmerkelwalsh.com

www.iblce.org

www.asha.org

www.aota.org

www.apta.org

www.adha.org

www.acatoday.org

References

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

https://talktools.com/pages/tots-tethered-oral-tissues scroll down and click on evidence-based practices

Copyright 2023