

Tongue and Lip Tie: A Comprehensive Approach to Assessment and Care

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Objectives

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After this presentation, learners will be able to:

- Learn lingual and maxillary labial frenula assessment strategies for infants
- Identify the incidence rate, available evidence and current thoughts around ankyloglossia
- Identify the impact of tongue/lip tie on breastfeeding
- Identify treatment strategies and aftercare ideas
- Describe the collaboration and team work involved when dealing with oral restrictions
- Identify community resources regarding tongue and lip tie concerns

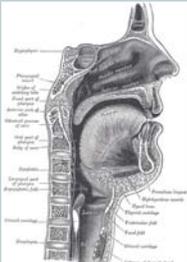
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Disclosures

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I have no conflicts of interest to declare.

Some slides shown may be slightly different than the handouts provided.



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Burning questions....

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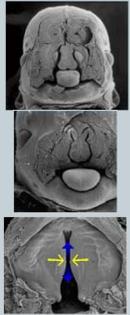
- Is tongue tie real?
- Is diagnosis and/or treatment a fad?
- What is the difference between an anterior and posterior tie?
- Is frenotomy evidence based?
- Why does ankyloglossia matter? What are consequences of an untreated tie?
- What is the incidence rate of ankyloglossia and is it increasing?
- How can tongue and lip tie be properly assessed for?
- What pre and post frenotomy care strategies are useful?

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Is tongue tie real? Why does it occur?

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- Yep, it's real (just like clefts and other congenital issues)! (ICD-10 = Q38.1)
- Ankyloglossia occurs when improper apoptosis during embryological development occurs.
- The tongue develops approx wk 4, by wk 6 the maxillary labial frenum and primary palate are developing
- Wk 8-9, the tongue helps shape the palate, apoptosis causes frenulum to 'die back' from the tip of the tongue.
- A 'tie' occurs when there is a disturbance during this stage of programmed cell death.



"Basic Embryology of Head and Neck". Chicago Medical Center. 2009-08-14. Retrieved from <http://emedicine.medscape.com/article/1289057-overview#tw2aab602> on 2015-01-14

Embryo Images - Drs Kathleen K. Sulik and Peter R. Bream Jr

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What messes up apoptosis anyway?

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- Environmental factors, genetic/epigenetic factors and physical injuries during embryogenesis may interfere with programmed cell death and thus induce malformations (Haanen, & Vermes,1996)
- Genetic or epigenetic triggers seem to cause mutations in the gene encoding transcription process (TBX22, etc) that factor into improper apoptosis, are closely linked to other orofacial deformities like clefts.
- Methylation is involved in apoptosis and TBX22 function. It is extremely sensitive to environmental stressors (viruses, chemicals, meds, nutrition, stress) and may be a regulating factor in normal facial development (Acevedo et al., 2010; Kantaputra et al., 2011; Andreou et al., 2007; Abbot, 1995)

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Should frenotomy really be controversial?

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Would you consider syndactyly normal and tell parent's that separation of the digits won't help function?

Think of ankyloglossia in the same way...improper apoptosis impacts function no matter what part of the body is affected!

Do we want suboptimal compensation or full functionality?



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Why does ankyloglossia matter? What are consequences of an untreated tie?

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- **Why does ankyloglossia matter?**
 - The evidence available has shown a direct correlation to tongue tie and breastfeeding issues, poor infant weight gain, maternal pain, and other health issues through the lifespan, etc (Agency for Healthcare Research and Quality (AHRQ), 2015).
- **What are consequences of an untreated tie?**
 - Cessation of breastfeeding, poor infant growth, dental/orthodontic issues, potential airway and orofacial issues, speech concerns, eating/swallowing issues, social/emotional concerns, etc (AHRQ, 2015; Dollberg et al, 2011; Fernando, 1998; Defabiani, 2000; Walls et al, 2014; Meenakshi & Jagannathan, 2014)
- **Won't it stretch?**
 - Nope. The collagen fibers identified in abnormal frenula are different and less elastic than the collagen fibers in unrestricted frenula.



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Why does ankyloglossia matter? What are consequences of an untreated tie?

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- "In infants with anterior or posterior ankyloglossia, there is a reported 25- to 80-percent incidence of breastfeeding difficulties, including failure to thrive, maternal nipple damage, maternal breast pain, poor milk supply, maternal breast engorgement, and refusing the breast..."
- "Adequate tongue mobility is required for breastfeeding, and infants with ankyloglossia often cannot overcome their deficiency with conservative measures such as positioning and latching techniques, thereby requiring surgical correction"...



(Agency for Healthcare Research and Quality (AHRQ), 2015).

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Johnny can stick his tongue out so he can't be tied...

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What are a few things the tongue needs to do in order to successfully breastfeed?

- **Elevate** – If the tongue can't get maximal elevation and the drop, enough negative pressure won't be formed and milk removal will be suboptimal
- **Cup** – If a tongue can't cup, a proper seal won't form causing ineffective milk removal, excessive aerophagia, poor bolus control resulting in s/s reflux
- **Extension** – If the tongue can't maintain extension through the whole feed, maternal pain/nipple damage will occur and milk removal will be compromised
- **Peristalsis** – Poor peristalsis leads to excessive compression (maternal pain) and poor bolus control, increased air intake, etc
- **Lateralize** – Poor lateral movements indicate restriction, poor tone, resulting in excessive jaw/gum use, increased maternal pain and infant feeding inefficiency

Compromised lingual movements = feeds less efficient for baby and mom

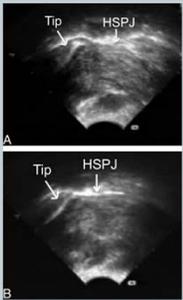
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Frenulotomy for breastfeeding infants with ankyloglossia: effect on milk removal and sucking mechanism as imaged by ultrasound

(Geddes et al., 2008)

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RESULTS: For all of the infants, milk intake, milk-transfer rate, LATCH score, and maternal pain scores improved significantly postfrenulotomy. Two groups of infants were identified on ultrasound. One group compressed the tip of the nipple, and the other compressed the base of the nipple with the tongue. These features either resolved or lessened in all except 1 infant after frenulotomy.



- **Photos:** Panel A shows a tongue-tied baby compressing the nipple tip. Panel B shows less compression following a frenotomy. (HSPJ = hard/soft palate junction) (Geddes, 2008).

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Ultrasound of how babies extract milk

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Is diagnosis and/or treatment a fad?

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- We are failing many families (75+% initiation in PNW, 25-30% duration/exclusivity at 3-6 mos).
- As breastfeeding rates increase, causes for Bf failure must be explored.
- Ankyloglossia is a real condition, not a fad BUT not every Bf issues is due to a tie.
- Proper assessment techniques and differential diagnosis are key so that over diagnosis and under diagnosis don't occur.



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What is the difference between an anterior and posterior tie?

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- Anterior ankyloglossia - prominent lingual frenulum and/or restricted tongue protrusion with tongue tip tethering
- Posterior ankyloglossia - lingual frenulum not very prominent on inspection, tight on manual palpation, abnormally prominent, short, thick, or fibrous, under-recognized



Photo courtesy of Catherine Watson Genna



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(Agency for Healthcare Research and Quality (AHRQ), 2015)

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Incidence of ankyloglossia

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Incidence rates as show in the literature

- Prevalence between 4% and 10% (Segal et al., 2007)
- 25- to 80-percent incidence of breastfeeding difficulties in babies with ankyloglossia
- Slightly more common in males compared to females (Griffiths, 2004)



Are incidence rates of tongue tie increasing?

- At present this is unstudied and unknown. Some researchers feel that epigenetic changes are occurring at a higher rates potentially increasing congenital anomalies and midline defects. This is certainly something to invest more time and resources in studying.



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Is frenotomy evidence based?

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- Yes! The current evidence all points to frenotomies being a beneficial and very low-risk procedure.
- Limitations exist around the quantity and quality of research and the logistics of creating an ethical study design regarding this intervention.
- Diagnostic criteria for defining or classifying ankyloglossia is not uniform (AHRQ, 2015; Segal et al., 2007)
- "Studies assessing the effectiveness of frenotomy for improving nipple pain, sucking, latch, and continuation of breastfeeding all suggested frenotomy was beneficial. No serious adverse events were reported" (Segal et al., 2007)



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What the research shows...

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- Overall, division of the tongue-tie babies resulted in improved feeding in 54/57 (95%) babies...This randomized, controlled trial has clearly shown that tongue-ties can affect feeding and that division is safe, successful and improved feeding for mother and baby significantly better than the intensive skilled support of a lactation consultant (Hogan et al., 2005)
- "Maternal self-efficacy, nipple pain, infant reflux symptoms, and the rate of milk transfer all significantly improves with lingual frenotomy with or without maxillary labial No complications were reported following any procedure" (Ghaehri et al., 2016)
- "All frenuloplasties were performed without incident. Latch improved in all cases, and maternal pain levels fell significantly after the procedure...." (Ballard et al., 2002)

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What the research shows...

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- "The frenotomy group improved significantly more than the sham group ($P < .001$). Breastfeeding scores significantly improved in the frenotomy group ($P = .029$) without a significant change in the control group..." (Buryk et al., 2011)
- There was a significant decrease in pain score after frenotomy than after sham ($P = .001$). There was significant improvement in latch after the frenotomy in these mothers ($P = .06$)...Frenotomy appears to alleviate nipple pain immediately after frenotomy" (Dollberg et al., 2006)
- "This review of research literature ...concludes that...frenotomy offers the best chance of improved and continued breastfeeding...the procedure does not lead to complications for the infant or mother." (Edmunds et al., 2011)

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A Frenulum vs. a Tie

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- Everyone has multiple frenula throughout the body
- Frenula are not the problem. The problem is when they restrict normal mobility and functionality.
- Visible assessment is not enough. Assessing function is the most important piece.



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Common signs and symptoms of tongue/lip tie

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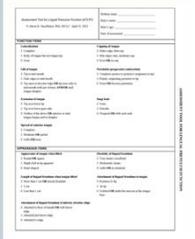
Infant Issues to Consider	Maternal Issues to Consider
<ul style="list-style-type: none"> • Latch is poor, hard to maintain, slips off, chews/gums • Prolonged feeds, sleepy at breast • Short feeds, infant fatigues • Nursing marathons "uses me like a pacifier" • Infant always hungry • Weight gain concerns • Poor seal, clicking, gag reflex • Colic, reflux, gas, yeast • Unable to hold pacifier/bottle feed • Not every baby will present with the same issues • Latch may look good but (tug, gum, scrape) 	<ul style="list-style-type: none"> • Nipple pain, compression • Incomplete breast drainage • Recurrent yeast, mastitis • Nipple blebs, plugged ducts • Low milk supply • Familial Hx of ankyloglossia • Has been working on "the latch" but nothing ever improves much • Seems like oversupply but regular management doesn't help • Feeling of infant gumming, flicking • Not every mom will have the same issues

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How can tongue and lip tie be properly assessed for?

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- There are several assessment tools. One commonly used, validated tool is the ©Hazelbaker Tool for Lingual Frenulum Function
- Learning to use such tools can help understand the lingual function.
- Other tools are also in the process of being created and validated



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How might restrictions of the lingual frenulum present?

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- Ankyloglossia compromises tongue functionality and may make the tongue:
 - Appeared bunched, retracted, pulled down in center
 - Create posterior tongue humping
 - Create poor-moderate elevation, extension, lateralization, cupping
 - Remain flat or low when infant is crying or gaping widely
 - Not reach the palate, creating a heightened gag reflex and poor tongue cleaning
 - Snap back after extension, peristalsis issues
 - Have a indent/cleft at tip...or not...



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Assessment video #1

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Assessment video #2

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Tongue Tie Classification

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- There are several classification systems - common one is the Coryllos, Genna, Salloum typing system:
- Type 1: attachment of frenulum to tongue tip
- Type 2: 2-4 mm behind tongue tip
- Type 3: attachment of frenulum to mid tongue
- Type 4: attachment at the base of the tongue

(AAP newsletter, 2004)

Remember, a classification system is not an assessment technique – just a charting/communication tool.



Photo courtesy of Catherine Watson Gema



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Photos courtesy of Dr. Lawrence Kotlow

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Maxillary Labial Frenulum Presentations

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Kotlow diagnostic classifications of maxillary frenum attachments
(photos used with permission of Dr. Lawrence Kotlow)



A



B



C



D

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Superior Maxillary Labial Frenulum Restrictions

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Some presentations of lingual restriction

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What do you notice?

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What do you notice?

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Slide 28

B6 show better pics, show my own pics
Melissa Cole, 12/20/2014

Other elements of assessment

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- Besides the tongue having mobility what else does a baby need to feed well?
 - Good oral tone – what can be too tight or too weak?? What oral tone and compensatory patterns are common in tongue/lip tied babies?
 - Structural support and health – beyond the mouth, what else should we check for? Bodywork needed?
 - Nervous system regulation – how can we assess ANS regulation?
 - Respiration – S:Sw:Br coordination is vital...how to assess??
 - Parent/infant connection – What does this look like?
 - Feeding plan – Is it sustainable, is it evolving?
 - Other ideas for assessment

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Anticipatory Guidance

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- Tongue/Lip tie related feeding issues can be a physical and emotional roller coaster ride for families.
- Providing anticipatory guidance on the following is vital:
 - What tongue and lip ties are
 - Choices regarding treatment/no treatment
 - Sustainable, evolving feeding plan (not what works for the LC...what works for the family!)
 - What the procedure will be like and what to expect after
 - Consequences of untreated ties
 - Expected time frame for recovery/potential reaction of infant (assess Hx painful procedures, temperament, state regulation?)
 - What post-care will look like, discuss soothing strategies
 - Acknowledgement of feelings/concerns

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Collaboration for treatment

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- Know who you are referring to.
 - What is their level of experience with ties?
 - What is their Tx style?
 - How well do they collaborate?
 - Are families getting mixed messages?
 - See if you can observe Tx
- When is the procedure done? ASAP, no benefit to delay (most cases).
- How is the procedure done?
 - Full assessment and discussion provided. After consent for Tx obtained then the frenum is numbed, baby swaddled, head immobilized, frenum released. Baby can feed immediately after. Aftercare instructions are given

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Tongue-Tie Treatment

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Scissors Release



Laser Release

Anticipatory guidance: Being able to tell families exactly what to expect during the treatment is useful. Become familiar with the entire process so that you can best support the dyads you are working with.
Photos courtesy of Dr. Bobak Ghaehri





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Appearance pre and post Tx

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Photos by Dr. Ben Sutter, Melissa Cole

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Newborn Scissors Tx Video

shared with permission, Dr. Bobak Ghaehri

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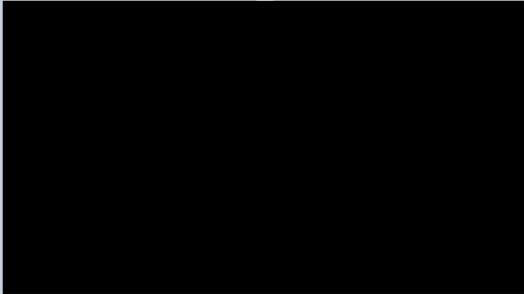


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3 week old – class III TT – laser

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Post frenotomy healing

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- Oral wounds heal quickly.
- Many of us find some type of aftercare is needed to prevent re-attachment and optimize function.
- Wound healing happens in stages:
 - Hemostasis/blood clot formation
 - Inflammation
 - Re-epithelialization
 - Granulation tissue formation
 - Remodeling of the connective tissue
- Oral motor work can be combined with the wound care to optimize healing and functionality. Every feed (4-6x/day min for 4+ wks)
- Goal is one better feed per day!



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Post frenotomy goals

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- Manage discomfort
- Compassionate aftercare (reduced stress = better healing)
- Ensure the wound heals with elasticity and scar formation is minimized
- Prevent the baby from developing an oral aversion or experiencing prolonged discomfort
- Work toward increased lingual mobility and functionality
- Work towards excellent oral motor skills (strengthen what is weak, tone down what is tense, etc)
- Promote healthy bonding and attachment between baby and caregivers
- Promote healthy autonomic nervous system regulation
- Ensure proper growth and provide the dyad with a sustainable feeding care plan as they work towards their goals (1 better feed per day!)



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Varied Appearances of Incision Site

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Post Frenotomy Visuals

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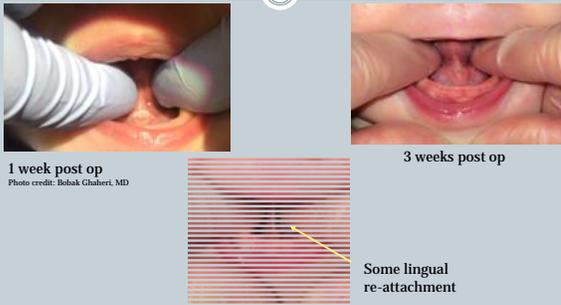
Day 1 post op

Day 3 post op

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Post Frenotomy Visuals

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1 week post op
Photo credit: Bobak Ghaheri, MD

3 weeks post op

Some lingual re-attachment

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Incision site appearance

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Labial frenectomy (scissors)

Labial frenectomy (laser)

Labial frenectomy (scissors)

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How often does reattachment occur

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- No published data
- My practice – less than 3%
- Online horror stories vs. reality
- Causes of reattachment (Tx, genetics, aftercare, stress, etc)

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Can a frenum re-grow?? Syndactyly and Tie comparison

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- Good analogy, caused by congenital issues, improper apoptosis
- Web creep is the most notable surgical risk – can lead to recurrence of partial syndactyly
- “The goal of syndactyly release is to create a functional hand with the fewest surgical procedures while minimizing complications” (Dao et al., 2004)
- “Web creeping” - the recurrence of abnormal webbing between digits that occurs because of scar contracture at the base of attachment or along incision lines
- Need for secondary surgery rates: 10% appox
- Keloid formation has been reported in 1% to 2% of cases
- (Chopra et al., 2013; Dao et al., 2014)

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PAIN RELIEF

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“Because neonates cannot verbalize their pain, they depend on others to recognize, assess, manage their pain”
(Pediatrics, 2000).

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What are short term consequences of painful experiences in the neonatal period?

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- There are a variety of diseases/conditions, diagnostic procedures and therapeutic procedures that can cause an infant pain. The more painful episodes an infant is exposed to can amplify the consequences of pain in infants (Matthew & Matthew, 2003; Ranger & Graunau, 2014).
- Some short term consequences include:
 - Irritability
 - ‘Fight or flight’ response, autonomic nervous system dysregulation
 - Fear/mistrust in caregivers/impaired bonding
 - Sleep/wake cycle disturbance
 - Changes in BP/HR, metabolic changes
 - Reduced caloric intake
 - Increased gastric acidity
 - Poor healing, compromised immunological function

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What are long term consequences of painful experiences in the neonatal period?

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- “Emerging studies provide convincing clinical evidence for an adverse impact of neonatal pain/stress in infants at a time of physiological immaturity, rapidly developing brain microstructure and networks, as well as programming of the hypothalamic-pituitary-adrenal axis...” (Grunau, 2013).
- Long term consequences include:
 - Alterations in plasticity of developing pain pathways
 - Heightened present/future perception of pain
 - Persistent alteration of stress system programming (depressed/elevated cortisol levels, HPA axis alterations)
 - Metabolic changes that impact absorption of fat, protein, glucose
 - Lower pain thresholds, especially in regions of prior tissue trauma
 - Reduced brain size in frontal/parietal regions, reduced maturation of white matter and subcortical gray matter
 - Alteration in brain microstructure and functional connectivity
 - Neurodevelopmental alterations (cognitive, motor and behavioral), greater internalizing behaviors (depression/anxiety)

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Non-pharmacological pain management strategies

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Here are some soothing techniques for babies that need it:

- Environmental interventions (dim light, warmth, smell, reduce noxious sound)
- Nutritive/non nutritive suck
- Breastmilk
- Skin to skin contact
- Facilitated tucking, swaddling
- Massage, therapeutic touch
- Music therapy



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Soothing through Sucking and Positioning...

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Pain relief properties of:

- Non-nutritive suck
- Breastmilk
- Breastfeeding







Pain relief through:

- Skin to Skin contact
- Facilitated Tucking
- Swaddling

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Feeling safe and connected helps healing...

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1. Significant moments of skin to skin holding
 2. Daily baby massage (preferably 2 short sessions a day)
 3. The TummyTime® method daily
 4. Baby sleeps within 2 feet of mom or dad
 5. Mom and Dad incorporate relaxing breathing activities with baby (exhaling longer than inhaling)
 6. Singing to baby
 7. Baby and parent engage in face time (smiling and looking at each other)
 8. Explaining how movement and different positions help baby calm and organize (preferences, dislikes, etc)
 9. Bodywork with an experienced practitioner
 10. Parents are taught how to listen to and support baby's crying

Shared with permission by Michelle Price Emanuel www.tummytimemethod.com

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Pharmacological Pain Relief Options

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Conventional options:

- Acetaminophen
 - Dosing based on weight, hard on liver (depletes glutathione),
 - Tylenol -no more effective than placebo in under 2 yr for pain relief and has serious risks from over dosage
- Ice
 - numbing/vasoconstrictive, no major risk, infant may dislike cold
- Oral Sucrose
 - Used to be thought of as significantly reducing discomfort, new evidence shows that only infant facial features change, not actual cortical response (Harrison et al., 2010 & 2012)

NOTE* Benzocaine oral jels NOT recommended due to risk of methemoglobinemia (potentially fatal, amount of oxygen in blood stream is greatly reduced. Risk worse for 2 and under. 29 reports since 2006, 15 of them in ages under 2 yrs.)

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Holistic Post-Frenotomy Pain Relief Options

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- Homeopathics**
 - Some commonly used for this are: aconitum, bellis perennis, bryonia alba, calendula, hypericum, arnica, staphysagria, etc – some are in gels, pellets, liquids, etc.
- Kids' Rescue Remedy**
- Herbal Options**
 - chamomile, st.john's wort, skullcap, lemon balm
- Misc Options**
 - co-bathing, skin to skin, breastfeeding/breastmilk



•Please work with someone familiar with pediatric dosing and CAM modalities. Natural does not always mean safe

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After care stretches and exercises: Positions

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- **Positions for holding baby**
 - There is no one 'right way'. Help it feel playful/natural to baby and parent and yet be effective.
 - Can try facing parent/provider, head in lap, walking around, etc.



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After care stretches and exercises: Positions

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After care stretches and exercises: Hands-on work

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- Make it a habit so parents don't forget (every feed, when switching between breasts, every diaper change, etc). Aim for min 4-6+ times per day for 3-4 weeks
- Do the 'fun' stuff first and then do the incision massages/stretches at end of session. Quiet/alert state is preferred.
- Make it playful! While the infant may be tender initially, it is possible to do the after care with love and respect.
- Many dyads are already traumatized by their pre-frenotomy tongue/lip tie ordeals. Let's help the healing process be a time to foster connection.
- Use reminders if needed (cell phone alarm, post-it note near changing table, etc).
- Oral motor work should target specific issues, not 'cookie cutter' approach
- It's okay to get in and out quickly when needed and linger when baby is enjoying the work.

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After care and exercises: Hands-on work

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Sample care routine:

- 'Beep bop boop bip' (chin nose, philtrum, chin tug)
- Jaw massage + chin tug
- Gum rub for lateralization
- Wipers on the palate (desensitizes heightened gag reflex)
- Tug-o-war and/or tongue stroke (cupping, extension)
- Side of tongue pushes
- Insert additional work here _____
- (Jaw inside/out, guppy, lip work, cheeks, etc)
- Use gentle pressure, lift lip/tongue up and 'rolling pin' massage over incisions site – massage the whole floor of the mouth

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After care stretches and exercises: Leo's Video

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After care stretches and exercises: Wesley's Video

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Feeding support post frenotomy

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- What issues may be lingering, more prominent, etc?
- What is too strong, too weak?
- Global tone issues? Work on 'core', TT
- Position + support
- Bottle questions?
- Stability and support post frenotomy is often needed. (arm out of a cast analogy). Stability can come in the form of careful positioning, a nipple shield, gentle facial support, pacing, etc.



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Breastfeeding support post frenotomy

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Breastfeeding support post frenotomy: Variations on Support Points

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Breastfeeding support post frenotomy: Cheek Support Video

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Rule of tens

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- When providing care always think about how you can be a healing presence.
- The "Rule of Tens" (National Association of Neonatal Therapists. Shared with permission).

How will the care I provide affect this baby in the next 10 mins, next 10 hours, next 10 days, next 10 weeks, next 10 months, next 10 years....

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Resources

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- My web site has an extensive list of articles, handouts and a bibliography of tongue and lip tie related articles. Please visit us at:
 - <http://www.lunalactation.com/articles-hand-outs/>
 (scroll down to tongue tie section)
- **contact info**
 - Melissa Cole, IBCLC, RLC
 - melissa@lunalactation.com
 - www.lunalactation.com
 - 360-830-MILK (6455)

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