Dear Health Professionals

I am sending this letter to health professionals who work closely with mothers and babies (including those who have worked with us). It is my hope that by sharing our experience we may be able to help increase awareness around the impact of congenital oral dysfunction and help others in similar situations.

My son 'A' was born in August 2013 in hospital after an uncomplicated vaginal birth with gas for pain relief. He could not attach himself to my breast straight after birth, but he did so easily with support from the midwife. I found learning how to breastfeed and getting a good attachment quite difficult. The hospital staff said this was normal and after a few days we were able to get a good attachment. My milk came in a bit late, but when it did 'A' gained lots of weight very quickly and we had no further breastfeeding issues. I considered myself very lucky to have such an easy start to breastfeeding.

After about 6 weeks when my milk supply stabilized, 'A' went from the 50th percentile to the 25th. His weight continued to drop to the 10th. However he was bright, alert and happy. He reached many of his developmental milestones early. I had him weighed regularly and was told not to worry, he was just little. I continued to feed him on demand - almost constantly – about 1.5-2 hourly during the day and anywhere from 2-3 hourly overnight. The feeds were long and slow with little time in between. His sleep was never particularly good and I had a lot of trouble settling him. He also had a lot of tummy/bowel pain, kicking his knees up a lot at night and waking up. All of this I was told is normal and I accepted the advice that it was. However for us there was something else going on that was missed.

By 3 months, 'A' was at the 5th percentile for his weight. With trouble sleeping, tummy pains, difficulty settling and frequent feeding, we were co-sleeping all night every night. This helped us enormously and I only wish we had done so sooner. It made the nights manageable and it's what got us through a very difficult phase.

With so much night disturbance, co-sleeping saved my sanity. We were both able to get some sleep, feeding was easier and I could comfort 'A' with an arm around him or a tummy rub when he needed it. It helped me be a more compassionate mother and strengthened the bond I have with him through this challenging time. I know that I would not have coped had we not co-slept. The only place I had any advice given to me about how to co-sleep safely was at an ABA meeting. In fact, I was actively discouraged from co-sleeping by several professionals, although it was clear to me that these professionals did not have an understanding of how co-sleeping can be safe and of its many benefits. Their judgment did make things harder and meant I began to disengage from some services designed to help me.

In November 2013 I was asked via my local ABA group if I would like to volunteer to be a part of a Lactation Masterclass with a highly experienced IBCLC from Brisbane. I went along and while demonstrating to the audience how to do an oral examination of an infant on my son, the IBCLC discovered that he had a posterior tongue tie as well as an upper lip tie. She explained how these ties could contribute to his low weight gain, tummy/bowel pain, poor sleep and frequent feeding. This was the first time any of the health professionals I had seen had identified this issue and been able to explain all of his symptoms.

This was overwhelming news to me as I would never have guessed we had a breastfeeding issue and suddenly we had decisions to make regarding a procedure to release the tie. We didn't have pain with breastfeeding and I think this is one of the main reasons no one picked up that there was something wrong prior to this. However, A's suck was so weak it was very ineffective at milk removal. Despite his tummy pains and trouble settling he also didn't cry very much. He is a beautiful soul.

Around the 4 months mark, 'A' had a growth spurt and the anatomy of his mouth changed his latch became worse. I became very aware that he was having trouble feeding.

We visited a local Adelaide doctor who is well known for cutting tongue ties, however he was unable to help 'A' with his posterior tie. Through the IBCLC we were referred to a Speech and Language Therapist in Hobart who has a special interest in tongue and lip ties and associated oral dysfunction. The Speech and Language Therapist referred us to a dentist in Melbourne who specialises in laser release of babies with tongue and lip ties.

It was not a decision we made lightly, but to nurture 'A' via breastfeeding was very important to me. In addition we were aware that he could experience future problems with starting solids, speech, possible digestive and airway issues – all potentially health issues for life. With little to lose and everything to gain, we flew to Melbourne for laser release.

The laser procedure was traumatic for us all. 'A' was swaddled and held by my husband while the dentist and a nurse performed the procedure (and I sobbed in the corner). I was aware that a lot of his crying was due to simply being restrained and held with his mouth open, but he was also in pain. It was very difficult for us and I'm sure we'll never forget it. 'A' was initially upset after the procedure and took a couple of minutes to settle after the procedure and then had a breastfeed. After a feed he was back to his old self and was all smiles at lunch, even putting toys in his mouth! I don't know if it was the new sensations in his mouth or if he were going to do it anyway but straight after the procedure he started putting everything in his mouth all the time.

His first few breastfeeds were certainly worse, probably due to the initial post-op pain and swelling, however after that he reverted to how he had fed previously. With support from my local IBCLC we worked on attachment and positioning and 'A's latch slowly started to improve. I also had several Skype consultations with the Speech and Language Therapist to work on rehabilitation exercises for his tongue.

The post-op rehab included some 'stretching' and massage exercises to ensure his mouth healed correctly. He coped with these really well and would even laugh occasionally when I put my finger under his tongue. I was so pleased that we had made the decision to go to Melbourne for laser release. Fortunately for families this laser surgery is now being offered for babies in Adelaide with a new monthly mobile clinic.

Below are some of the changes I observed over the months following the procedure. Many of the issues that resolved after the release were things that I had assumed were normal (e.g. slipping off the nipple and dribbling milk when feeding).

First week after release

- tongue extended slightly more;
- top lip could now flange when feeding (totally new!);
- suck still weak;
- slightly less dribble of milk when feeding;
- reduced snuffling at night (caused by milk in his sinuses when feeding lying down);
- dummy (which we use for sleep only) still fell out easily but he started to move it all around his mouth

Second week after release

- it became more obvious to me that he was full after a feed;
- his hunger cues were also more apparent, rather than the more constant grazing;
- tired cues also became more apparent!

Third week after release

- tongue extended significantly more;
- no longer gaging on fast letdowns;
- noticeably stronger suck;
- no more sliding off the breast during feeds;
- longer stretches between feeds at night.

Fourth-Fifth weeks after release

- less mucousy poo which had been common;
- less tummy discomfort;
- doing more new movements with his tongue including like pushing the whole tongue forwards to the lips;
- starting to try to crawl so sleep regressed a lot!

Sixth week after release

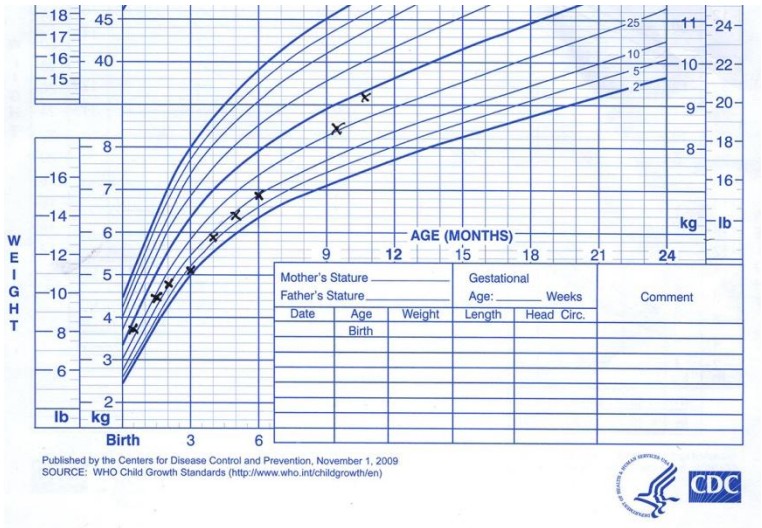
- started to stick tongue out a long way just prior to latching on;
- one month of consistently good weight gain – first time since his birth (this despite him being 5.5 months and exclusively breastfed, no solids yet);
- started solids with baby led weaning at 5.5 months with no choking or gagging

3 months after release

- easier to switch off and fall asleep due to a release of tension in his head after the revision of restricting ties

4 months after release and beyond

- at 8 months of age, 'A' was at the 20th percentile for his weight, after being as low as the 5th percentile at 3 months of age prior to the release.
- at 10 months he was just over the 25th percentile and at 11 months he was just under the 50th!



Our early months were stressful but I am so very grateful for the professionals and other parents we have met who helped us to navigate uncertain waters, identify and treat the problem and successfully breastfeed.

I do believe A's poor weight gain should have been investigated fully early on, including a proper oral assessment. There are two key reasons for a baby receiving a lack of calories and not gaining weight. One is poor milk supply (not us) the other is poor baby suck ability which leads to poor milk supply (us!). In hindsight it seems odd that these issues were not considered given how common tongue and lip ties are, affecting 15-25% of babies and the impact that they have on breastfeeding success or cessation.

I have to say that it is probably only due my diligence, devotion and commitment to A's well being that he remained well, though skinny. If I had not been prepared to feed him continually day and night (and this means being willing to co-sleep) the outcome for 'A' may not have been so good.

Besides breastfeeding difficulties, it was very distressing to have an unsettled baby who wasn't sleeping well and was obviously in pain and I can understand how many other mums also suffer emotionally and mentally. To be told this is "normal" by so many professionals was at odds with my intuition and gut feeling. I found that the limited knowledge of tongue tie with the health professionals I encountered had a massive impact on my experience as a mum in the early months.

In the references listed below there is an article titled *Understanding the Experiences of Mothers Who Are Breastfeeding an Infant with Tongue-Tie: A Phenomenological Study.* The women in this study described a somewhat harrowing journey, which was at odds with the natural experience they had anticipated. They encountered health professionals who were found to have limited knowledge of tongue tie and its potential effect on breastfeeding and were unable to provide appropriate advice concerning their breastfeeding difficulties. Sadly, this was also my experience.

Research estimates that that 15-25% of babies have tongue or lip ties and this affects breastfeeding and also bottle feeding (due to poor seal) and can have other effects beyond this. Many mums struggle, give up or wean early because of unresolved difficulties and lack of appropriate assessment and diagnosis and even in these cases issues can continue with bottle feeding.

I know all the health professionals I have come across care deeply about the women and babies they see. I hope our experience exposes them to the different ways that oral issues and tongue and lip ties can affect both mothers and babies so they can increase their awareness and look for professional development opportunities to learn appropriate oral assessment so they can refer for further help as needed and can continue to support mums and babies through breastfeeding and beyond.

Please feel free to share our experience for learning and professional development. I hope sharing helps others and increases awareness around some of the factors that can have a dramatic impact on breastfeeding success or cessation. Thank you for taking the time to read this.

Regards
'L'

Some notes on anatomy, tongue ties and breastfeeding

In babies that have a defective anatomy because of a restrictive tongue movement the peristaltic motion of normal progressive tongue contractility is defective. This in turn reduces the entire gastric digestive reflex wave that follows the swallow. Babies with tongue tie are compromised, they often take on more air than normal because of the lack of appropriate suction and seal, and have shorter feeds because of tiring so their intake of milk is not quiet complete and less coordinated. This in turn affects their digestive mix, enzymes and acids leading to very windy babies who often have gut pain. The compensations that these babies make to survive can be a mixture of inefficient or ineffective behavior at the breast. This structural dysfunction cascades into various individual body stressors for the infant, poor sleep, tummy pain, wind, aspiration, leaking and reflux.

Furthermore, at around 12 weeks of age the mother's breastmilk production converts from endocrine to autocrine. If a baby has been ineffectively removing milk this is a crucial point and is often the time at which babies start dropping weight percentiles and babies continue to feed very often but ineffectively, contributing to further fatigue.

At 4 to 6 months of age the neck elongates causing the posterior tongue to drop into the emerging oropharynx. This creates a lowering of the larynx and hyoid. This is often another classic time when breastfeeding become more difficult and difficulties can be noticed with babies who are bottle fed. The epiglottis and soft palate in effect move away from each other thus changing a previous closer relationship. At this point some tongue tie infants have increased difficulty with swallowing coordination, which may also be evident from the start too.

In terms of difficulty settling it is thought that the restriction of tongue and lip ties can also cause excess tension in the scalp, head and neck. This changes the input into the cranial nerves and is thought to increase physical discomfort and alertness making it harder for babies to switch off and down-regulate to sleep. This discomfort combines with other disturbances like breathing issues (including sleep apnoea) and reflux, both common in tongue tied babies. It can take several months for improvements in this area to be seen as it takes significant time for a structural change to translate into a more functional neurological behavior.

It can be very normal human biology for babies – especially newborns - to feed frequently day and night. However, babies in tribal communities who feed 16 times per day are thriving babies who feed short and sharp because they are strong. 'A' fed frequently because his suck was ineffective. Some bowel discomfort is often considered normal too however this disappeared in the weeks after the tongue was released. Bowel pain can be due to hunger (us), overload (not us), excess or trapped wind from the poor seal (us) or poor peristalsis (us).

See references and links below for further information, in particular http://www.kiddsteeth.com/articles.html (lots of great articles here). I have also included an image of tongue ties, including a posterior tie.

In addition the Australasian Society for Tongue and Lip Ties was founded in January 2014 by Holly Puckering and Bridget Ingle. Their *Cutting Edge Symposium* will run from 23-24 October 2014, Gold Coast QLD (http://www.breastfeedingconferences.com.au/conference_details.php?conferenceId=47)

References, websites and further reading

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Coryllos, Elizabeth. et al. *Congenital tongue-tie and its impact on breastfeeding*. American Academy of Pediatrics Newsletter, Breastfeeding Section, Summer 2004.

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Genna, Catherine Watson. *Supporting sucking skills in breastfeeding infants*. Jones & Bartlett Publishers, 2012.

Hazelbaker, Alison K. *Tongue-Tie: Morphogenesis, Impact, Assessment and Treatment*. Aiden and Eve Press, 2010

Hogan, M. et al. *Randomized, controlled trial of division of tongue-tie in infants with feeding problems*. Journal of Pediatric Child Health 41(5-6), 2005, pp. 246-250.

Knox, Isabella. *Tongue Tie and Frenotomy in the Breastfeeding Newborn*. NeoReviews 11(9), 2001, pp. 513-519.

Kotlow, Lawrence A. *Diagnosing and Understanding the Maxillary Lip-tie (Superior Labial, the Maxillary Labial Frenum) as it Relates to Breastfeeding*. Journal of Human Lactation 29(4), 2013. pp 458-464

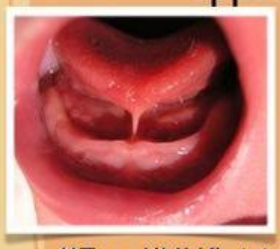
http://brianpalmerdds.com

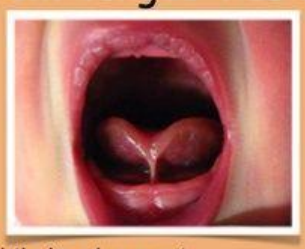
http://www.kiddsteeth.com/articles.html

http://nurturedchild.ca/index.php/breastfeeding/challenges/tongue-tie-and-lip-tie/

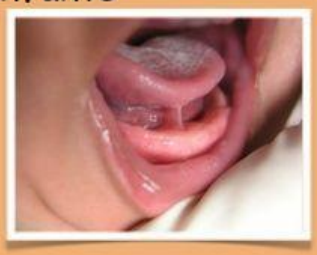
http://www.tonguetie.net

*Kotlow Diagnostic criteria (one) for clinically apparent tongue-ties in infants

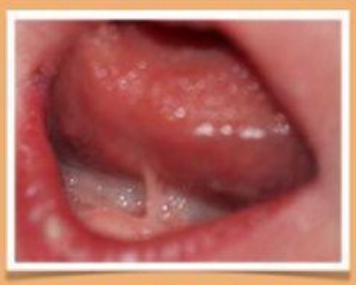




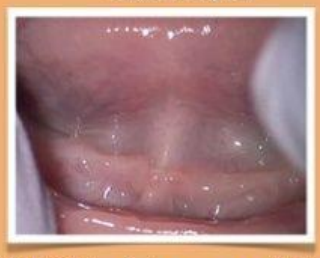
**Type I(*4LK) -total tip involvement



Type -II (*3LK) Midline-area under tongue (creating a hump or cupping of the tongue)



Type III (*2LK) Distal to the midline.The tongue:may appear normal

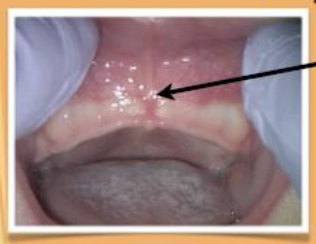


Type IV (*ILK) Posterior area which may not be obvious and only palpable, Some are submucosally located

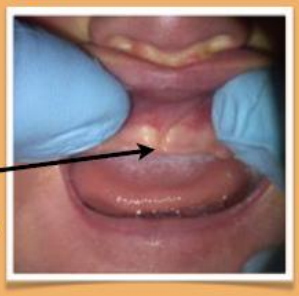
**Lactation consultants diagnostic criteria

Lawrence Kotlow DDS 2011

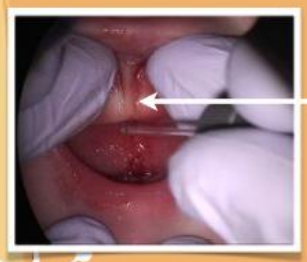
Kotlow infant and newborn maxillary lip-tie diagnostic classifications



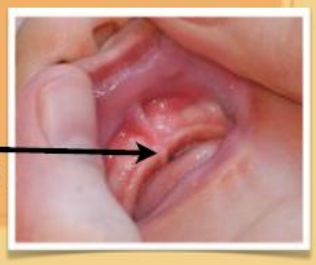
Class I
Minimal visible Attachment



Class II
Attachment primarily into the gingival tissue



Class III:
Inserts just in front of anterior papilla



Class IV
Attachment just into the hard palate or papilla area

Lawrence Kotlow DDS 2011