

# Tongue-tie in babies

# Information for Parents

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This booklet has been written for parents and is based on the knowledge and experience I have gained since training to divide tongue-ties in 2011. A lot of the information currently available on the internet is from the USA. The information in this booklet focuses on the situation in the UK. I hope that it explains what tongue-tie is, how it is treated and help to clarify some of the confusion surrounding this common, but under recognised condition. I hope that parents will find it useful and am happy to receive comments from parents on ways this information can be improved upon.

I would like to thank the mothers who contributed their thoughts and comments to this booklet and all the babies I have cared for and learnt so much from.

A single copy of this booklet may be downloaded and printed for personal use only.

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**Disclaimer:** The information contained within this booklet is not a substitute for professional advice. If you have concerns about your baby's feeding or tongue-tie then you should seek help and support from an appropriately qualified practitioner.

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# What is tongue-tie?

Tongue-tie occurs when tongue movement is restricted by the presence of a short, tight membrane (known as the lingual frenulum) which stretches from the underside of the tongue to the floor of the mouth. The lingual frenulum is a remnant from the pre-natal period. As the tongue differentiates from the floor of the mouth, as the baby develops in the womb, the cells under the tongue regress backwards from the tip of the tongue leaving a small strand of tissue at the back (the lingual frenulum). This strand of tissue is visible when the tongue is lifted and is a normal part of anatomy. However, when it is short, tight, and inelastic, extends along the underside of the tongue or is attached close to the lower gum it will interfere with the normal movement and function of the tongue and is a tongue-tie.

There are different types of tongue-ties. Some are very obvious due to the appearance of the tongue. Where the frenulum is attached close to, or at the tongue tip a notch will be visible in the tip of the tongue and the tongue will appear heart shaped or forked. However, where the frenulum is attached further back along the underside of the tongue it will be less obvious. Although it may be clearly seen if the tongue is lifted, perhaps during crying. Some tongue-ties, known as posterior tongue-ties, can be hidden at the base of the tongue, sometimes under the lining of the mouth, and are easily missed at first glance. These ties are quite easy to identify by pushing a finger tip under the midline of the tongue and pressing against the base of the tongue to see if there is resistance or by sweeping the finger laterally under the tongue, across the base, and feeling for a bump or 'fence'.



Picture of a tongue-tie (they don't all look like this)

There is no universally agreed way of classifying tongue-tie. Some practitioners will classify according to where the frenulum is attached on the under surface of the tongue. So, where the frenulum is attached half way back along the underside of the tongue it will be classified as 50%, a quarter of the

way back from the tip as 75% and so on. Others refer to type with type one being a tongue-tie attached at the tongue tip (100%), type 2 being 75%, type 3 being 50% or less and type 4 being 'submucosal' (under the lining of the mouth). For simplicity tongue-ties can be classified as anterior (near the front) or posterior (at the back). However, whilst some practitioners classify only submucosal tongue-ties as posterior, other practitioners will refer to any tongue-ties of about 50%, or less, as posterior.

In terms of how tongue-tie affects an individual, the type or appearance really doesn't matter. A hidden sub-mucosal tongue-tie can cause similar feeding issues to the very obvious heart shaped 100% tongue-tie. It is the level of restriction in tongue movement and function which is important and should form the basis of treatment decisions.

# What causes tongue-tie?

Tongue-tie has been around for a long time. References are made to it in medical texts dating back to the 17<sup>th</sup> century. The incidence of tongue-tie probably varies between different populations. Studies have been done on incidence. But varying definitions of tongue-tie have been used so it is difficult to get an accurate picture. A study in Southampton suggested it affected around one in 10 babies. It is certainly a very common contributor to breastfeeding issues.

Despite this the cause of tongue-tie is not known. It certainly appears to run in families and is more common in boys.



# Signs and symptoms of tongue-tie (Babies and mothers may experience some, but not all of these)

# For the mother

Nipples which look misshapen, ridged or blanched after feeds

Nipples that are sore/blistered/cracked/bleeding/bruised Mastitis and blocked ducts

Low milk supply

Over supply of milk

Exhaustion from frequent/constant feeding

Distress from failing to establish breastfeeding

# For the baby

Restricted tongue movement – baby may be unable to poke his tongue out or lick his lips. During crying the tongue may remain in the floor of the mouth or just the edges may curl up forming a 'dish' shape.

Inability to open mouth wide when attaching to the breast resulting in biting/grinding behaviour

Unsettled/fussy behaviour when latching to the breast and during feeds

Coughing on the milk flow

Difficulty staying attached to the breast

Falling asleep at the breast before the end of a feed

Frequent or very long feeds

Excessive early weight loss/ poor weight gain/faltering growth

Clicking noises and/ or dribbling during feeds

Colic, wind, hiccoughs

Reflux (vomiting after feeds)

# (Babies and mothers may experience some, but not all of these signs and symptoms.)

# Quotes from mothers

- 'I was kept in hospital because my baby wouldn't latch... so I expressed my colostrum and fed her by syringe'.
- *'He fed constantly. It was 6 weeks of hell. I just kept going. I thought this was normal'.*
- 'My supply had dropped dramatically so I had to express and top up with a syringe and SNS.'

- 'The first week was really bad. My nipples were bleeding.'
- 'My baby was losing weight and kept falling asleep at the breast.'

There is a myth that tongue-tie only causes feeding difficulties for breastfed babies. However, bottle-fed babies can suffer with similar symptoms to those listed above.

# When to suspect your baby has a tongue-tie which is affecting feeding

In some babies a tongue-tie will be obvious. The tongue may be heart-shaped or forked. It may not lift from the floor of the mouth at all when baby cries or only the edges of the tongue, not the tip, may lift forming a 'dish' or 'v' shape. You may have never seen your baby lick his lips or poke out his tongue. You may notice that when baby opens his mouth the tongue forms a 'hump' at the back. Your baby may have difficulty achieving a wide gape when latching on. He may slip off the breast.

Persistent nipple soreness, which does not resolve when you have had help to improve positioning and attachment, suggests baby may be tongue-tied. Mums often describe the nipple pain experienced during feeding and associated with tongue-tie as 'chomping', 'grinding' or 'rasping'. It frequently takes the mother's breath away and renders her unable to speak when the baby first latches on. Babies with tongue-tie are often unable to extend their tongues fully which means they do not cushion the gum underneath the nipple with their tongue and they are not able to scoop up a large mouthful of breast and hold it securely in the mouth. The lips of tongue-tie babies are often blistered where they have been using their lips to compensate for their inability to hang onto the breast securely with the tongue and maintain a deep latch.

Nipples often look pinched 'wedge shaped similar to a new lipstick' after feeds. This pinching may also restrict blood flow to the nipple during feeds leaving it white in colour after feeds. Once the baby comes off the breast blood will flow back through the nipples and this can cause throbbing pain or 'electric shock', burning or stabbing pains deep in the breast tissue.

This deep breast pain is often mistaken for thrush infection. I have seen many mothers and babies who have received treatment for a suspected thrush infection when the problem has actually been a tongue-tie. Thrush infection is rare in young babies under 6 weeks old, usually occurs after a period of pain-free feeding, and affects both breasts. Treatment for deep breast pain associated with thrush infection involves the use of the oral drug Fluconazole at high doses for a period of 10-14 days. This drug has a long half life which means it can accumulate in the body and as it passes into breast milk there are concerns about the effects of this accumulation in young babies. So, treatment is not advised until positioning and attachment difficulties have been addressed, tongue-tie has been excluded and the diagnosis confirmed by taking swabs from the nipples and baby's mouth. So if a midwife, HV, breastfeeding counsellor or GP is suggesting you need treatment for thrush make sure that tongue-tie is excluded first by someone skilled in tongue-tie assessment.

For more information see the link below:

# http://www.breastfeedingnetwork.org.uk/dibm/Thrush\_and\_Breastfeeding\_Feb\_2013.pdf

Excessive weight loss in the first few days of life, or slow weight gain later on despite constant feeding or associated with a baby who is very sleepy at the breast, are also indicators of tongue-tie.

Babies with tongue-tie are often very inefficient at the breast. They will suck many times before taking the occasional swallow. This is very tiring so sucking bursts will be short. The baby will fall asleep at the breast and have to be stimulated to keep feeding. Feeds may be very short. But, because the baby isn't getting enough milk to satisfy their needs they may feed very frequently or even constantly.

Some babies are unable to maintain the latch at the breast, slipping down the nipple and coming on and off the breast. These babies often make a clicking sound at the breast or whilst feeding on the bottle. A fast 'let down' reflex and/or oversupply can exacerbate this problem. Tongue–tie babies are very poor at managing milk flow and will often cough and choke on the 'let down' at the start of a feed and sometimes will refuse to go back to the breast after a few minutes of being overwhelmed by the flow. Conversely when the flow slows down or where flow is slow due to low supply tongue-tie babies can struggle to keep the flow going and can get very frustrated, pulling and fussing at the breast. Evening cluster feeding episodes can be particularly lengthy and stressful for babies and mums due to the slower evening flow. The ability to elevate the tongue tip, create a wave-like movement from the front of the tongue to the back and form a seal around the nipple are crucial if babies are going to manage flow effectively. All of these functions may be compromised in a tongue-tie baby.

Excessive wind, abdominal discomfort and reflux may also be associated with tongue-tie. Because of the difficulties babies with tongue-tie have, with regulating flow and maintaining a deep latch and seal at the breast, they tend to gulp on the milk flow. Parents can often hear the milk 'hitting the stomach' and the babies gulp loudly for a few sucks and then have to come off the breast to catch their breath. These babies often groan and squirm at the breast and find it difficult to settle peacefully between feeds.

Parents may find looking at this information by lactation consultant Catherine Watson Genna on spotting on tongue-tie useful:

http://cwgenna.com/quickhelp.html

#### **Diagnosis of tongue-tie**

Newborn babies are screened for a variety of abnormalities, including congenital hip dysplasia, heart murmurs, cataracts and cleft palates during the routine newborn assessment, carried out shortly after birth, by a paediatrician or midwife. However, this check does not include assessment for tongue-tie. Even if you specifically ask for your newborn to be checked for tongue-tie it is highly likely that the person doing the check will not have had specific training in tongue-tie assessment and will therefore not be able to confirm, with any certainty, whether tongue-tie is present or not.

# A mother's experience

'I asked the MW doing the newborn check if she was tongue tied and she said no. I went to the GP and other MWs. But it wasn't until she was two weeks old the HV spotted it when she was crying'.

Many of the signs and symptoms above can be linked to poor positioning and attachment, or other issues such as oversupply or food sensitivity in the case of wind/colic and reflux. However, if your baby displays any of the signs and symptoms listed above it is important to seek help from someone with expertise in the assessment and management of breastfeeding and feeding issues related to tongue-tie.

This will usually mean seeking help beyond that offered by your midwife, HV or GP as these mothers found...

'We were very, very lucky. We decided to go to a local group on day 3 which happened to be run by an LC who also divides tongue-tie.'

'My friend suggested tongue-tie. Accessing information on tongue-tie locally was not easy. I had to discover most of it via the internet... It was hard to find good resources and sort through the less useful stuff.'

Basic midwifery and health visitor training includes very little training in breastfeeding and tonguetie may not get mentioned at all. When I trained as a HV in 2002/2003 I received just 3 hours training in breastfeeding management. Some universities and hospitals now offer a 2 or 3 day breastfeeding management training course (based on the UNICEF Baby Friendly Initiative) to their student and qualified midwives and health visitors. However, this training is not offered everywhere. Where staff are offered this training they may find it hard to access due to difficulties in being released from their regular duties. There is often a lack of understanding around the significant impact increasing breastfeeding rates could have on the health of mothers and babies, and the cost savings that could be made for the NHS. General Practitioners and Paediatricians fare no better. Infant feeding does not appear on their curriculum at all.

So, doctors, midwives and health visitors are not always in a position to offer good quality, evidence based information and support on breastfeeding issues and often parents will be on the receiving end of lots of conflicting advice. Data collected from my clients indicates that only one in four babies with a tongue-tie are being diagnosed by a healthcare professional. The same number are being identified by parents themselves. Breastfeeding Counsellors and Lactation Consultants identify around 40% of the tongue-tied babies I see. So, it may be sensible to seek out an experienced breastfeeding counsellor or lactation consultant.

### What is a breastfeeding counsellor?

A breastfeeding counsellor (BFC) is a woman who has breastfed her own babies and has trained to provide skilled help and support to other breastfeeding women. The training is very in depth and typically lasts 1-3 years. In the UK there are 4 organisations that provide this type of training – The Association of Breastfeeding Mothers (ABM), The National Childbirth Trust (NCT), La Leche League (LLL) who call their counsellors LLL Leaders, and Breastfeeding Network (BfN) who call their counsellors Breastfeeding Supporters. All of these organisations are charities and their counsellors give their time free of charge. They run National Helplines and provide support groups, and in some cases home visits too. They are experts in normal breastfeeding and common difficulties and provide mother-to-mother based support. The 4 charities responsible for BFC training require that BFCs keep up to date by attending study days, etc. Some BFCs are also midwives and health visitors.

# What is a Lactation Consultant?

Lactation consultants (LC) have a background either in breastfeeding counselling and/or nursing, health visiting, midwifery or medicine. They have to complete an intensive period of in-depth study on all aspects of breastfeeding, including complex difficulties and sit a 6 hour exam to qualify. To be eligible to sit the exam they also have to demonstrate that they have considerable experience, running into 1000s of hours, in supporting breastfeeding women. Once qualified a LC can use the letters IBCLC after their name. They have to recertify every five years by providing evidence of continuing professional development and re-sit the exam every ten years.

The titles Lactation Consultant and Breastfeeding Counsellor are not protected in law so anyone can give themselves this title. So it is absolutely essential that parents check that the person they are consulting with is appropriately qualified. This can be done by checking the register on the International Board of Lactation Consultant Examiners website <u>www.iblce.org</u> for LCs or by contacting the relevant charities for BFCs. Lactation Consultants specialising in tongue-tie can be found on the Association of Tongue-tie Practitioners website <u>www.tongue-tie.org.uk</u>.

#### **Tongue-tie assessment**

Where a parent, healthcare professional, BFC or LC suspects a baby may be tongue-tied the baby should be referred on to someone who is both skilled and knowledgeable in breastfeeding and tongue-tie. Currently many parents are being told their babies are not tongue-tied when they are because the person looking at the baby is not experienced enough and lacks the relevant training in both breastfeeding and tongue-tie to be making this judgement.

Any practitioner, whether a healthcare professional, BFC or LC, who is assessing for tongue-tie should start with the taking of a thorough birth and breastfeeding history. They should then observe a feed, although if babies are being seen in busy breastfeeding groups or clinics, only part of a breastfeed may be observed due to time constraints.

Suck and tongue function also needs to be assessed. This assessment involves more than simply putting a finger in the baby's mouth to see if the baby can suck it. The Assessment Tool for Lingual Frenulum Function (ATLFF) developed by Alison Hazelbaker (1993) looks at the way the tongue cups the finger and the motion of the tongue as well as how the tongue move within the mouth, including how it moves from side to side (lateralisation), how far the tip of the tongue lifts and how far the baby can poke (extend) the tongue. This tool also assesses tongue appearance. But this is secondary to function as a tongue can look relatively normal but still have deficits in function and be impacting on feeding. Conversely I have seen babies with obvious heart shaped tongues who have been feeding very well because the frenulum is long and stretchy and not restricting movement significantly. The ATLFF scores for tongue appearance and function, with scores of 8 or less on appearance and 10 or less on function indicating a significant tongue-tie.

There are other tools and methods available for assessing tongue-tie in infants. Some as basic as sweeping a finger under the tongue to see if you can feel a 'fence' or a 'speed bump'. However, the ATLFF is the only published tool that has demonstrated reliability and validity in infants up to 12 weeks of age.

# Treatment

The most commonly used method for dividing a tongue-tie in the UK and indeed around the world involves clipping the frenulum with a pair of sterile scissors. This procedure is known as a frenotomy or frenulotomy. The baby is wrapped securely in a towel or blanket so they cannot wriggle or put their hands to their mouth. The head is then held still by a parent, nurse or other helper. The practitioner performing the procedure lifts the tongue using the finger or fingers of one hand. (Some practitioners prefer to use a Brodie Director, a small metal spade shaped instrument with a central slit to isolate the frenulum and lift the tongue). With the scissors in the other hand the practitioner slides the blades under the tongue so they are on either side of the frenulum and snips. Some tongue-ties divide well with just one snip, others will require 2 or 3 snips depending on how tight, thick and far forward the frenulum is.

Parents' biggest concern about the procedure is usually the fear that the baby will be in pain. But most babies tolerate the procedure very well. There are very few nerve endings in the area of the frenulum and babies sometimes sleep through the procedure, suggesting it does not cause too much pain. Of the several hundreds of babies I have treated and seen treated I can only recall 2 who showed signs of discomfort when the tongue was snipped. Although a lot of babies will cry when wrapped and held still, and those that are awake do usually protest briefly about having their tongues lifted. Most babies cry for less than a minute afterwards and settle quickly once back in mum's arms and at the breast or on the bottle. Reassuringly Allison Hazelbaker, author of the assessment tool mentioned earlier, had her tongue tie snipped without any local anaesthesia at the age of 41 and has reported that there was only a momentary sting. I usually see more upset and distress when immunise babies than I do after tongue-tie division.

Some practitioners do use local anaesthetic gels or teething gels when carrying out the procedure. But some babies find this distressing as they don't like the taste and it prolongs the whole procedure. There is also the concern that some babies may react adversely to these gels. Because they numb the mouth it can make feeding difficult after the procedure which can prolong distress and bleeding. So, most practitioners I know don't use them. For older babies (over about 3 months) I usually suggest a dose of Calpol is given about half an hour before the procedure. However, I'm not sure how much difference this makes. For older babies Calpol and Ibuprofen can be used as per the instructions on the bottle after the procedure if they appear sore or upset. But most babies do not require this.

This procedure using scissors is commonly used up to around six months of age in the UK. But some practitioners will perform it on older babies depending on their temperament and tolerance and the absence of teeth. Southampton General Hospital where I trained have treated babies like this up to about nine months of age.

An alternative to scissors, used widely in the United States, is laser frenectomy. This has the advantage of cauterising the tissue, reducing bleeding. For this reason it is thought it may be possible to do a deeper divide when dealing with more posterior ties where bleeding is more of a concern. However, there haven't been any studies published comparing the two methods. Furthermore, laser treatment is more expensive and difficult to access. There are currently only two private dental practitioners in the UK using it and training has to be undertaken in the United States. Laser frenectomy is not available on the NHS to my knowledge.

# Who does the procedure?

In the UK the National Institute for Health and Social Care Excellence (NICE) state in their Guidance on the treatment of tongue-tie that the procedure should be performed by a registered healthcare professional which means a healthcare professional registered with the General Medical Council (doctors), Nursing and Midwifery Council (Nurses and Midwives), General Dental Council (Dentists) or the Health Professionals Council (which would include professionals such as speech therapists, physiotherapists, etc). Lactation Consultants are not registered healthcare professionals so those offering tongue-tie division are generally registered nurses or midwives too and use their status as registered healthcare professionals, not as lactation consultants, to perform the procedure.

#### **NHS and Private Services**

Within the NHS the majority of tongue-tie services are run by paediatric, oral or maxilla-facial surgeons who obviously have excellent surgical skills and experience. However, tongue-tie division is a simple and safe procedure so many hospitals are choosing to train and use nurses and midwives to perform tongue-tie division. Surgeon time is limited and expensive so this can lower costs and make a service more accessible to patients. Most nurses and midwives in the NHS performing tongue tie division are also lactation consultants or have specialist skills and knowledge in breastfeeding. I believe this has significant advantages over seeing a surgeon with no experience in assessing and supporting breastfeeding. A frequent issue encountered by parents accessing treatment through the NHS is that the surgeon they see does not fully understand the impact of tongue restriction on breastfeeding or how this affects both mum and baby. So what looks to them like a relatively minor physical anomaly can have a devastating effect on the baby's well being and the mother's breastfeeding experience.

It is a sad fact that some of the medical profession, due to the lack of training I mentioned earlier and our western culture, still do not acknowledge the health and social benefits of breastfeeding for mum and baby (and indeed wider society) or understand how important breastfeeding is for mothers and the emotional and psychological effects of not being able to do so. Mothers are too often being told to give up breastfeeding by well-meaning doctors, rather than go through with a simple procedure which may mean they can continue to breastfeed for as long as they choose.

Seeing a nurse/midwife who also has lactation training means that you will get a more thorough assessment and understanding of the breastfeeding issues, help after the procedure with latching the baby on and information on how to continue with the feeding and resolve any difficulties in the days to come.

A lot of tongue-tie divisions done privately in the UK are done by people like me who have nursing or midwifery qualifications and are usually certified lactation consultants too. Obviously, unlike the NHS, we charge for our services. But in return we offer prompt appointments, often within 48 hours. Whereas NHS waiting lists can be anything from a few days up to 6 weeks. We can also visit babies at home, which can be helpful in the early days when getting out of the house can seem impossible. NHS appointment times range from 20-45 minutes. Whereas private providers will spend at least an hour, and usually significantly longer, for consultations. They will take a comprehensive medical, pregnancy, birth and feeding history and spend time afterwards supporting mothers with breastfeeding and putting together a plan to address any remaining issues. Most private providers also offer follow up support. This may be as a further home consultation or through a clinic or group, or via phone, email or even Skype. There may be additional charges for this support. Although I offer phone, email and group follow up free of charge. I often remain in contact with mums for several months after the procedure.

Some surgeons offer private treatment which I find particularly helpful for the more difficult tongueties or babies with complex medical histories. We also have two private dentists in the UK offering laser treatment as mentioned earlier. Private surgeons and dentists sometimes work closely with lactation consultants and some will have a lactation consultant in their private clinic with them to support mums. Surgeons and dentists are often more expensive than nurses and midwives who provide the procedure and are obviously not in a position to offer the intensive, ongoing support that practitioners like I can.

When choosing who to treat your baby or where to have treatment it may be helpful to seek experiences from other parents. Whether you are having the procedure done privately or through the NHS you should feel able to ask lots of questions. Ask the person providing the treatment about their professional qualifications and experience. Private practitioners should offer proof of their qualifications and insurance. Choosing a private practitioner who is local to you can make a lot of sense as you should then be able to access them easily for follow up. Follow up support is important so find out what your practitioner offers as this can vary.

Information about tongue-tie practitioners, including a directory of private and NHS provision, can be found at <u>www.tongue-tie.org.uk</u>.

# **Effectiveness of treatment**

Parents are often told by doctors, midwives and health visitors that tongue-ties don't affect breastfeeding and that even if they do treatment is too dangerous or doesn't work.

NICE evaluated the research around the effectiveness for treating tongue-tie in babies with breastfeeding issues and published guidance in 2005 which clearly states:

Current evidence suggests that there are no major safety concerns about division of ankyloglossia (tongue-tie) and limited evidence suggests that this procedure can improve breastfeeding. This evidence is adequate to support use of the procedure.

Information written for the public on this guidance can be accessed at

# http://www.nice.org.uk/nicemedia/live/11180/31410/31410.pdf

For parents wishing to review the evidence themselves this link will take you to a summary of the review conducted by NICE along with details of the studies.

# http://www.nice.org.uk/nicemedia/live/11180/31409/31409.pdf.

Despite this I still come across healthcare professionals who are telling parents that research has shown the procedure is ineffective and that NICE Guidance does not recommend it. Or another favourite myth amongst some healthcare professionals is that the NICE Guidance has changed recently. It absolutely has not and parents can check this for themselves by going onto the NICE website www.nice.org.uk and searching for tongue-tie.

These two more recent randomised controlled placebo trials found that tongue-tie division was associated with an improvement in breastfeeding:

- 1. Berry J, Griffiths M, Westcott C. A double-blind, randomised controlled trial of tongue-tie division and its immediate effect on breastfeeding. *Breastfeeding Medicine*, 2012, 7: 189-193.
- 2. Buryk M, Bloom D, Shope T. Efficacy of neonatal release of ankyloglossia: a randomized trial. *Pediatrics*, 2011; 128: 280-286.

It must be remembered though that no medical treatment or procedure is effective for everyone and tongue-tie may not be the only factor interfering with breastfeeding. Birth trauma, milk supply issues, illness in the mum, prematurity or illness in the baby are just examples of factors that can coexist alongside tongue-tie and jeopardise breastfeeding. So all of these issues need to be addressed too, making access to skilled breastfeeding support essential after the procedure.

#### What mothers have said

- 'After the procedure my baby smiled for the first time. He uncurled his toes and fists. The tension just left him.'
- 'I am so happy we got the tongue-tie treated. I feel sure our breastfeeding relationship would have ended has we not sought help and taken action.'

#### Complications associated with tongue-tie division

Until the 1950s, when bottle feeding was promoted and became the most common feeding method, tongue tie division was carried out fairly routinely in the UK. As tongue-tied babies often manage bottle feeding with more ease than breastfeeding the procedure stopped being performed. But it came back into practice during the mid 1990s when breastfeeding rates started to increase and mothers became better informed. Since then I would guess that in excess of a hundred thousand procedures have been carried out in the UK, with hundreds of thousands more being carried out in other countries.

Complications are rare with professional experience and published studies pointing to tongue-tie division (frenulotomy or frenectomy) being safe. NICE have identified these potential risks: bleeding, infection, ulceration, pain, damage to the tongue and submandibular ducts and recurrence of the tongue-tie.

# Bleeding

Bleeding is usually light after tongue-tie division and usually resolves within a couple of minutes. A few babies do not bleed at all. Most practitioners request that babies attend for their appointment hungry as feeding the baby at the breast or on a bottle immediately after the procedure is by far the most comfortable and effective way of stopping the bleeding. The action of sucking naturally puts pressure on the wound. When babies refuse to feed or are unable to latch to the breast then bleeding may go on for a bit longer than a couple of minutes. In this situation I will usually get the baby to suck my gloved finger or a parent's finger to help calm the baby and stem the bleed. Although most babies even if they are crying, will stop bleeding spontaneously within 5 minutes. Where bleeding is heavy or prolonged pressure can be placed over the wound using two fingers and held for a least 5 minutes. This pressure can be repeated as necessary and is usually effective. The practitioners caring for the baby will make a decision on when to intervene further with bleeding based on the amount of blood loss and age and condition of the baby. I have heard of adrenalin soaked gauze being used very effectively to stem bleeding when feeding and pressure have failed. I have also heard of a handful of cases where the wound has been cauterised or stitched. But most of the very small number of babies who bleed will stop with no further intervention beyond pressure.

Practitioners are usually careful to ensure that there aren't any bleeding disorders in the family, such as Haemophilia or Von Willebrands Disease, that the baby is not at risk of Vitamin K deficiency and that the baby does not have any health issues which may increase the risk of bleeding or complicate its management. Parents need to be aware that many practitioners, including myself, will be reluctant to divide tongue-ties in babies who have not had vitamin K and are exclusively breastfed.

Parents do need to prepare themselves to see a little bit of blood and should make the practitioner doing the procedure is aware if this is likely to be difficult for them to cope with or make them feel faint. Particularly if they are planning to have the procedure done in the home where parents are expected to help with holding the baby's head.

# Infection

Infection after tongue-tie division is rare. At Southampton General Hospital where I trained to do tongue-tie division there has been only one reported case of the wound becoming infected. This

baby was not unwell with the infection, continued to feed and responded well to a course of antibiotics.

In 2010 a more serious case occurred at a hospital in Essex where a young baby developed a serious infection and subsequently died after a tongue-tie procedure. The baby contracted bacteria called Klebsiella Oxytoca. However, it would not usually be expected to cause serious infection. Tragically in this case, the baby developed septicaemia. The news report relating to this can be accessed here <a href="http://www.bbc.co.uk/news/uk-england-essex-22081044">http://www.bbc.co.uk/news/uk-england-essex-22081044</a>.

If the wound becomes infected after the procedure one would expect it to weep (as happened with the Southampton case) and the area around the wound may look swollen and inflamed. However, I have never seen a case of infection and I don't know of many practitioners who have as it is very rare. Healthcare professionals who are not familiar with tongue-tie division sometimes mistake the white patch, which looks similar to a mouth ulcer that appears as the wound heals as infection. But it is completely normal. As you can see from the picture below the ulcer can look quite large.

# Ulceration

As already explained as the wound heals it turns white (sometimes with a yellow/slightly greenish tinge) to form a patch resembling a mouth ulcer and this is normal. This usually occurs within 48 hours and disappears within a week to 14 days. As it heals it can appear to be lifting at the edges and in some babies the edge can look dark red/orange. This is all part of normal healing.



Picture of a large ulcer 2 days after division of a severe anterior tie (normal healing but usually they are smaller than this one)

#### Pain

Most babies do not appear to find the actual procedure painful. Although they may object to being wrapped and held still. Afterwards some babies do go through an unsettled period where they find feeding difficult and cry more than usual. This often only lasts a few hours. But some babies can be generally upset and not quite themselves for up to a few days afterwards. It is not always clear if these babies are in pain or struggling to get used to their more mobile tongue. The majority of babies will continue as if nothing much has happened to them, especially the very young babies. If you think your baby is in pain you can give them infant paracetamol if they are over 8 weeks old in accordance with the instructions on the bottle. For babies under this age medical advice should be

sought before giving anything. Lots of skin to skin and other close contact through cuddles and baby wearing is often the most effective, natural and safe way of easing any upset or discomfort.

Concerns about any pain or upset which may be associated with the procedure, and will be temporary, have to be balanced against the distress being caused by the symptoms related to the tongue-tie. A lot of babies with untreated tongue-tie suffer hours of distress and discomfort due to wind and reflux. Furthermore many babies have to struggle, and may have to feed for exhaustingly long periods, in order to get the milk they need to survive from the breast or bottle. Feeding should be pleasant and a source of comfort for babies. For tongue-tied babies this is often not the case:

• 'She was very windy. The breast wasn't a place of comfort for her and this was upsetting for us both.'

# Damage to the tongue and sub mandibular ducts

This is quite rare. The sub mandibular ducts are the salivary ducts in the floor of the mouth. I have seen one case where a salivary duct was damaged causing a localised swelling in the floor of the mouth. This resolved on its own. I have also seen a photo of a case where the floor of the mouth was slightly damaged during the procedure and caused abnormal healing which meant the baby had to have a further minor procedure with scissors to divide the tissue which had adhered together. I have never seen damage to the tongue.

# Recurrence

This is by far the most common complication practitioners see and is a source of much controversy. Some practitioners maintain that if the tongue-tie is divided completely then reoccurrence is unusual. Whilst others maintain that almost all tongue-tie will reoccur unless a regimen of massaging and stretching of the wound is employed after division.

When a tongue-tie is divided completely the mucosa (lining of the mouth) opens up to form a diamond (or rhomboid) shaped wound and the practitioner will not be able to feel any remaining restriction or tension under the tongue. However, all of the practitioners I have spoken to have experienced recurrence, even when they know they achieved a very good divide. Whilst those promoting massaging and stretching after division are often adamant that there will be recurrence without it, none have published any studies or data to back their claims as yet. It also has to be remembered that the studies showing frenulotomy to be effective in improving feeding, referred to earlier, did not involve the use of stretching and massage.

Certainly some recurrences are down to incomplete division of the tongue tie in the first place and I have spoken to practitioners who have been taught to only cut half way back for fear of damaging the muscles, nerves and blood vessels at the base of the tongue. In most cases where some of the tongue-tie or rather frenulum remains, it has been by accident. I have done some procedures where the baby has been very small or had a very tight jaw, or where bleeding has obscured my view and I have taken a cautious approach and done a second procedure at a later date.

But most recurrences are exactly that. The frenulum comes back. The mechanism by which this happens is another subject of debate. Some practitioners believe recurrence is the result of the raw wound edges simply adhering and healing back together. However, I have seen a baby who had their

tongue tie divided at 3 months for nipple pain by a very competent practitioner. Mum went on to have 11 months of pain free feeding before the pain returned and on checking there was a very obvious frenulum under the tongue once more which was causing significant restriction in tongue movement. I have come across other similar cases where feeding has deteriorated several months after the procedure, after a period of significant improvement. So, I am not convinced that all recurrence is the result of the edges healing back together again. Another theory is that all tongue tie wounds form scar tissue and it is this tight, inelastic scar tissue which then restricts tongue movement. However Allison Hazelbaker in her book 'Tongue-tie: Morphogenesis, Impact, Assessment, and Treatment' (2010) states that the formation of scar tissue is not supported in the literature and is an 'unreasonable concern'. A third theory is that the tongue tie 're-grows'. Damaged nerves, blood vessels and even milk ducts can regenerate so is this possible? A fourth theory is that dividing the tongue tie actually allows further frenulum buried deep in the muscle at the base of the tongue to move forward. I have certainly seen a very fine, white strand buried deep in the tissue within the diamond shaped wound after tongue-tie division which has seemed inaccessible on occasion and I can imagine that this may move forward over time. But the fact is, despite some of the claims made none of us really know.

What we do know is that all practitioners have cases of reoccurrence, with those of us in private practice being much more aware of this sometimes than our NHS colleagues. This is because most NHS providers do not carry out follow up, or if they do it is very short term. Most NHS services do not offer division beyond 3 months of age so those with recurrence are often over the age limit so come to private practitioners for second procedures.

### What can be done to stop recurrence of tongue-tie

#### Post procedure wound management

Reducing the risk of recurrence is not only controversial, it is highly emotive. None of us wants to see babies put through multiple procedures. Most practitioners seem to agree that babies who latch well afterwards and breastfeed frequently (at least 3 hourly is suggested) are less at risk as the tongue movements involved in breastfeeding will keep the tissue mobile. Babies who receive bottles, anecdotally, seem more at risk of recurrence.

The use of stretching and massage is something which is practiced widely in the United States. But not very widely in the UK. Different practitioners recommend differing regimens. Some recommend simply stretching the wound to open it back up into a diamond shape two or 3 times a day for 5 days. Others recommend stretching more often (before every feed) for up to 3 weeks. Some go further and say that stretching alone isn't adequate and that the wound has to be stretched open and then massaged horizontally back and forth or in a circular motion for up to 30 seconds. Other practitioners talk about simply pressing a finger back against the wound 2- 5 times a day.

The links below will take you to information on some of the wound management regimens being recommended:

http://kiddsteeth.com/dental\_topics.html#breastfeeding\_health

http://www.drjain.com/

http://nurturedchild.ca/index.php/breastfeeding/challenges/what-to-expect-after-tongue-tie-andlip-tie-release/

# http://vimeo.com/55658345

There is currently no consensus and furthermore no published evidence to support the efficacy of any of these methods. Of concern is the fact that many parents report that this type of after care is distressing for the babies and seems to cause some pain and sometimes bleeding. It is often suggested that parents use teething gel before massaging to ease discomfort or try again later. But a lot of parents I have had contact with have found it difficult and have given up after a few attempts or have done the massage much less frequently than advised. Even after parents have done massaging many times a day for several weeks there have been reported cases of recurrence.

It is extremely difficult to encourage parents to do something which may cause distress when we don't know what really works and what is safe. However, we do know that recurrence is an issue that needs addressing with rates of recurrence quoted as being at least 4% overall and as high as 20% for posterior tongue-ties (Watson Genna, 2013).

So I currently suggest the use of techniques such as the exaggerated latch to achieve a deep and effective latch, offering the breast at least 3 hourly for the first week after the procedure, and using finger feeding or a lactation aid to give supplements if needed to avoid bottle use. I also suggest cranial osteopathy.

# How cranial osteopathy can help

It is an interesting fact that the vast majority of the babies I see for tongue-tie division have had a birth that has been complicated in some way. Interventions during labour are known to be associated with an increased risk of feeding difficulty after birth. Babies born by forceps or venous, babies who have been breech or had another abnormal presentation, babies born by section, babies born with the cord around their neck and babies born after very prolonged or rapid labours are all at increased risk of feeding issues. Medication used during labour for pain relief can affect the baby making them sleepy and disinterested in feeding. Epidurals immobilise mums following delivery making tending to the baby and positioning him at the breast more problematic. Stitches can also make it harder for mum to get comfortable whilst feeding.

The pressure exerted on a baby's head by the normal contractions of labour is substantial and leads to the head moulding (the soft bones of the skull overlap and bend) as it comes through the birth canal. When things don't go quite to plan and interventions are used this pressure can be prolonged or abnormally strong and lead to distortion of the bones in the skull. These babies sometimes have obvious asymmetry of the face or head. As the baby proceeds along the birth canal the head has to twist and turn and this can result in compression and tension in the neck. This abnormal head moulding and neck tension can have long term consequences for the baby and impact on the ability to feed effectively. It can affect the ability of the baby to open the jaw wide, to use the tongue correctly, and suck effectively and rhythmically, to co-ordinate suck/swallow/breathe. It can also make it difficult for the baby to tilt their head back in order to latch and the associated strain and discomforts can make them very tense and even resistant at the breast. Compression in the neck and head can also cause nerve impingement. I have seen babies with restricted tongue extension

after birth that have had improvements in their ability to poke out their tongue after a couple of session with a cranial osteopath. It is my understanding that this is due to the release of the nerves which connect to the tongue (the ninth cranial nerve).

But it is not just the effects of birth which can result in tension within the head and neck. Tongueties themselves can cause abnormal strain within the mouth, face and jaw. Many mums report that their tongue-tied baby never achieves a wide open gape and this is due to the tension caused by the tongue-tie which prevents the baby relaxing and dropping the jaw fully to open the mouth wide.

Cranial osteopaths can identify and treat the effects of head moulding, neck tension and tongue-tie through gentle manipulation. However, it needs to be remembered that the effects of cranial treatment may be impaired if the tongue-tie remains untreated.

Just like post procedure wound management regimens, there is no published evidence on the efficacy of cranial osteopathy. But there is a large body of anecdotal evidence and parents find it acceptable as the vast majority of babies enjoy it.



#### What to expect after treatment

We would all like tongue-tie division to offer an instant solution to breastfeeding issues. For some mums and babies it is. But this is not usually the case and parents embarking on having tongue-tie division, and the professionals and breastfeeding specialists supporting them, need to go into it with realistic expectations. Babies can sometimes be quite unsettled after the procedure and in a few cases feeding will deteriorate before it gets better. Studies done on the efficacy of tongue-tie division generally report an improvement in breastfeeding within a few days for between 70-100% of babies. However, these studies have largely looked at the more obvious anterior type of ties.

Deterioration in feeding is often seen in babies when the tongue-tie is particularly short, thick and tight. Babies practice sucking and swallowing on the amniotic fluid in the womb during the third trimester of pregnancy. This practice helps them to learn how to use their tongues and develops tongue tone in preparation for feeding once born. However, if movement of the tongue is restricted by a tongue tie this period of practice and preparation is going to be of limited value. For babies with the most restrictive tongue ties division will leave them with a fully mobile tongue. But it will be low in strength and tone and the baby may struggle initially for a few days to feed effectively. However, each time they feed tone will improve and there are simple exercises that can also be done to improve tongue tone and placement. Remarkably most babies will improve and start sucking more effectively within a couple of days. Although fully efficient, pain free feeding may take longer to achieve.

My experience has been that in general babies with the more obvious, anterior ties improve more quickly than those with the more posterior ties, where it may take a few weeks to see changes for the better. This may be partly due to the fact that these types of ties are more likely to be diagnosed late which means associated difficulties such as lowered milk supply are more prevalent. There are also theories that the older a baby is treated the longer it may take for them to re-learn how to use their tongues correctly. However, I have known some older babies who have instantly improved their latch after division. So age is not the only factor.

Exactly why some babies do better after division than others is not clear. Feeding is a complex skill and involves other oral structures, not just the tongue. The fact the tongue has been restricted can impact on these other structures. For example, free movement of the tongue shapes the palate so babies who have had a tie often have abnormal high arched or 'bubble' palates. So even after tongue-tie release some mums will still experience some nipple pain due to the palate. These mothers will need help with optimising positioning and attachment. Neurological issues, birth trauma, prematurity and physical abnormalities can also affect the ability of babies to suck and feed. But these issues are not always easy to identify. I am currently offering an assessment clinic in conjunction with an osteopath and speech therapist which I hope will enable me to better understand and identify those babies who may struggle more after division and to offer more effective interventions to support them.

# Support

If you are planning to have your baby's tongue-tie divided expect it to take a few weeks to see significant improvements in feeding. Identify where you can get help and support from. The support of a lactation consultant or experienced breastfeeding counsellor with be invaluable. Try to find someone who has experience with tongue-tie babies. You will probably have to pay for lactation consultant support. But breastfeeding counsellors often run local breastfeeding groups offering free support. You may be able to access a lactation consultant through the NHS via your local hospital. But the support they are able to provide may be very limited.

As I have already said some babies may benefit from cranial osteopathy. This is not available on the NHS so has to be paid for privately. I have seen some good results with cranial osteopathy. But osteopaths are not lactation specialists and cannot provide information and support on positioning, latching, building up milk supply, suck training, etc. So it makes little sense to access an osteopath without accessing skilled lactation support at the same time.

Breastfeeding groups are also a great place to get help and encouragement after tongue tie division in those early days when things are perhaps not as good as you would like. As tongue-tie is quite common you are bound to run into other mums of tongue-tied babies in your local group with whom you can share experiences. If you go to a breastfeeding group and don't hear tongue-tie mentioned it probably means the staff running the group are not aware of or experienced in tonguetie and aren't looking for it.

Facebook and other online forums can offer another source of information, support, reassurance and encouragement. But remember that those posting on these groups can come from all over the world so some of the information may not be relevant to the UK and comments made are usually personal opinions rather than fact. So, it is always worth checking information out.



# Other issues related to tongue-tie

# Tongue-tie and Speech

The link between tongue-tie and speech is just as controversial as the link between tongue-tie and feeding issues. The medical profession are generally reluctant to accept a link and it is not a subject that receives much attention during the training of speech therapists. However, there are lots of studies, both old and new, linking the more obvious types of tongue-ties where the frenulum is attached close to the tip of the tongue with pronunciation difficulties. Although the decision to offer treatment to babies should be made based on the presence of a feeding issue, I am sure that early division of tongue tie in babies does help prevent speech issues later on. For those babies, not treated in infancy, who go on to develop speech problems tongue-tie division can still be performed. But under general anaesthetic. For further information take a look a speech pathologist's Carmen Fernando's website <a href="http://tonguetie.net/">http://tonguetie.net/</a>

# Tongue-tie and dental issues

As previously stated the movement of the tongue shapes the palate so babies with tongue-tie can have high arched palates which means there is less space for teeth and can lead to overcrowding. Tongue-tied children and adults may not be able to sweep their tongues around their mouths fully in order to clear trapped bits of food away from the teeth predisposing them to dental decay. The late Brian Palmer's website has more information on dental issues, as well as other tongue tie related problems www.brainpalmerdds.com.

# A word on lip tie

Increasingly I am being asked about upper lip ties. I think this is partly because lip ties are clearly visible to anyone when the top lip is lifted. Tongue-ties are often not so obvious. As around 80% of babies with tongue ties also have upper lip ties it is essential that parents noticing upper lip ties in their babies have the child checked for tongue tie.

To understand how an upper lip tie may affect feeding we need to look at how the baby attaches to the breast. Older breastfeeding literature talked about both the upper and lower lips flanging during breastfeeding to form 'fish lips'. The idea that 'fish lips' are a good sign still litters the internet and popular literature on breastfeeding. However, ideas about the role of the upper lip have changed. In actual fact only the lower lip should flange. If the latch is optimal the upper lip should be in a neutral position (See Supporting Sucking Skills by Catherine Watson Genna, 2013, p 34).



Baby with top lip in neutral position



Baby with top lip flanged

Babies who flange the top lip are doing so because they are compensating for a shallow latch due to poor positioning or a tongue tie. They are using the top lip to hang onto and compress the breast. Obviously if the top lip is tied the baby will find it harder to employ the lip to compensate for the tongue tie. However, if the tongue-tie is divided the need to flange the lip will be eliminated and the presence of a lip tie will become irrelevant. Currently there is no published research to support that lip ties affect breastfeeding or that treating them improves breastfeeding.

The idea that upper lips ties are significant and need to be treated seems to originate largely from the United States where dentists perform many of the tongue-tie divisions and increasingly divide upper lip ties at the same time. Dentists initially appear to have developed an interest in upper lip tie because it can predispose breastfed babies to dental decay if they continue to breastfeed through the night once teeth come in. The tie can act as a pocket where milk can pool and cause decay. (E. Kernerman IBCLC, Live Tongue-tie Webinar, 3/4/14).

There are also suggestions that lip ties may cause speech issues. I have not seen any research to back this up or found any speech therapists who feel they are significant in terms of speech.

The strongest indications for treating a lip tie seem to be to prevent dental decay or gaps in the front teeth when adult teeth come through. Some dentists in the UK are starting to refer older children for treatment before orthodontic work. Because of the lack of evidence to support a link between lip tie and feeding difficulties the NHS does not offer lip tie division for feeding issues. However, some NHS Trusts will treat older children to prevent dental problems. So if you have concerns about upper lip tie I would suggest talking to your dentist.



# **Further reading**

#### Articles from La Leche League on tongue-tie

http://www.lalecheleague.org/nb/nbmarapr96p41.html

http://www.llli.org/nb/nbmarapr06p64.html

http://www.llli.org/nb/nbsepoct08p11.html

http://www.llli.org/nb/nbmarapr02p56.html

http://www.llli.org/llleaderweb/lv/lvaprmay02p27.html

#### **News articles**

http://www.telegraph.co.uk/women/womens-health/3353116/Breastfeeding-The-kindest-cut-ofall.html

http://www.bbc.co.uk/news/health-26199591

http://www.dailymail.co.uk/health/article-2615462/I-breast-feed-baby-One-five-babies-borntongue-tied-like-womans-son-undiagnosed-years.html

#### **UNICEF** information on tongue-tie

http://www.unicef.org.uk/BabyFriendly/Parents/Problems/Tongue-Tie/Division-of-tongue-tie/

#### Information on tongue-tie from Mervin Griffiths, Consultant Paediatric Surgeon, Southampton

http://www.uhs.nhs.uk/Media/Controlleddocuments/Patientinformation/Childhealth/TongueTieMr Griffithsthoughtson-patientinformation.pdf

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