Information For Parents On Tongue-Tie In Ireland 2021.

This information leaflet for parents was complied in response to the lack of information on tongue-tie and its management from an Irish Perspective. Any feedback or requests for further information is welcomed, contact details at end of document. A PDF version is available on request.

What is a tongue tie?

Tongue- tie is a piece of tissue located under the tongue, that is too short, tight, thick, inelastic or attaches too far forward in the mouth. It restricts normal tongue range of motion and so impacts function of the tongue. For infants, function generally refers to eating, breathing and sleeping.

Most people have a piece of tissue called a lingual frenulum under their tongue and it is a normal part of anatomy. However, this tissue must prevent the tongue from being able to move properly AND impact function for it to be considered a tongue-tie.

A lip-tie is similar to tongue-tie in that it is also a string of tissue under the upper lip, may be restrictive and less commonly affect feeding. Buccal Ties refer to tight tissue either side of the upper cheek. There is less evidence for the treatment of lip and buccal ties.

Posterior tongue-tie

Lip-tie

How common is Tongue-Tie?

Estimates of 3-10% prevalence has been reported, but this question is difficult to answer because the way we classify and recognize tongue is not standardized.

Due to increasing breastfeeding rates, new research and social media, there is increased awareness of tongue-tie, and this has contributed to more diagnoses. The rates of tongue-tie division have increased exponentially in the past decade.

What causes it?

The string of tissue under the tongue, known as a lingual frenulum, is a remnant of normal development of the baby inside the womb. As the baby grows, a process called apoptosis causes the tissue to move back towards the base of the tongue. It has been suggested that failure of apoptosis is a cause of tongue-tie.

Genetics also play a role: tongue-tie is more common in families in which one family member is already affected, and is more common in male infants.

Two small research studies suggested that types of folic acid supplementation are linked with tongue-tie. There is no strong evidence for this currently, and folic acid supplementation has been proven to dramatically reduce serious conditions like spina bifida, a problem with a baby's spinal cord. All women should take folic acid supplementation up to 4 months before and until 12 weeks after the start of pregnancy.

How can tongue-tie affect infants?

Research showing ultrasound pictures of breastfeeding have revealed that the tongue plays an important role in breastfeeding, and if the normal tongue movement is restricted, the feeding pattern changes – a baby can have poor latch or seal around the nipple, they can swallow air or leak milk, or gag, choke or cough. They can transfer milk inefficiently at the breast, leading to falling asleep and short feeds, or conversely exceptionally long feeds, almost leading onto one another. They can be very fussy and squirming while feeding, and can be fussy after, often as a result of reflux symptoms and swallowed air.

Although it is common babies with tongue-tie and their mothers to have problems breastfeeding, sometimes is does not affect feeding at all. Sometimes, tongue-tie can cause no problems for a number of weeks, and then cause symptoms, often when the milk supply becomes less driven by mum's mums' hormones and more driven by the baby's intake of milk at the breast. It can also cause feeding problems for bottle fed infants, typically around gas, reflux and managing milk flow.

Potential challenges for the breastfed baby with a tongue tie include

- Difficulties in achieving and maintaining deep attachment to the breast
- Weight loss or challenges to gain weight
- Restless and unsettled feeds
- Noisy or clicking sounds during the feed
- Tiring easily and falling asleep on the breast
- Colic or reflux symptoms as a result of swallowing air during feeds

Challenges for the mother breastfeeding a baby with a tongue tie include

- Distorted nipple shape after a breastfeed (and be lipstick-shaped)
- Bleeding, damaged or ulcerated nipples resulting in nipple pain
- Incomplete milk transfer by the baby resulting in engorgement and /or mastitis
- Persistent nipple pain during feeds despite addressing any positioning or latch issues.
- Persistent breast pain, which can often be misdiagnosed as thrush, but is actually due to blood flow returning to the breast after being compressed.

Potential challenges for the bottle-fed baby with a tongue tie include

- Frequent small volume feeds (can seem like the baby is constantly feeding)
- Very long feeds, but little milk transfer
- Slipping off the teat
- Dribbling of milk during feeds
- No improvement when the teat is changed for a different type
- Difficulty keeping soother in mouth
- Colic or reflux symptoms as a result of swallowing air during feeds

Potential challenges for a weaning baby with a tongue tie include

- food refusal
- spitting food back out
- difficulty moving on from very thin consistency foods
- choking or gagging while feeding

There is evidence that tongue tie can causes issues with speech, especially articulation of some consonants like 'R' and 'L. Tongue-tie can limit the tongue's ability to remove food from the teeth, resulting in poorer dental hygiene and cavities, and can result in malocclusion (misalignment or incorrect relation between the teeth of the upper and lower jaws when they approach each other).

There is also evidence that tongue ties can be related to poor sleep, mouth breathing, sleep apnoea (pauses in one's breathing while asleep), poor facial development, poor posture and head and neck pain and strain in adulthood.

What to do if you or your infant has symptoms of tongue-tie

If you are having trouble breastfeeding, then lactation support is important. There may be a number of issues other than tongue-tie affecting breastfeeding, and simple measures to improve positioning and latch may resolve the issues. Many of the symptoms associated with tongue-tie, like wind, fussiness and reflux. can be caused by other issues, like fast let down, low milk supply, issues like allergy or intolerance, so seeking medical help is important. If these symptoms are present, it is important that the baby is checked for tongue-tie as part of an overall assessment.

Breastfeeding support is available from a lactation consultant, or IBCLC, breastfeeding counsellor, breastfeeding support groups, or health professionals trained in lactation support. You can find help on websites https://www.alcireland.ie/find-a-consultant/, https://www2.hse.ie/services/breastfeeding-support-search/, https://www.cuidiu.ie/branches_webpages, https://www.lalecheleagueireland.com, https://www.friendsofbreastfeeding.ie

Currently in Ireland, there is little or no training of medical professionals regarding tongue-tie. There are many reasons for this. There have been huge advances in tongue-tie management in the last 15 years. The research on tongue-tie is so new that awareness is not widespread in the medical community. The evidence we have is also not yet of high enough quality to create widespread change. More research is needed.

Assessment of tongue-tie does not form part of the hospital discharge check, 2 or 6 week Postnatal check. For this reason, it is important that you seek an assessment by someone specifically trained in tongue-tie. This person may be a lactation consultant, paediatrician, ear nose and throat doctor, GP, dentist or feeding specialist.

Assessment of tongue-tie

If an infant is breastfed, the first step is to have a full breastfeeding assessment. If bottle-fed, an observation of a feed should take place.

Tongue-function is assessed by examining inside a baby's mouth using a gloved finger. It involves looking at the mouth, the palate, lips, cheeks, and both above and below the tongue. Tongue movement and function is then assessed, often by examination of suck of the examiner's gloved finger in a younger infant. The baby's alignment, and overall body shape and movement are sometimes examined for signs of strain or tension. Findings are often then used to generate a score, such as The Hazelbaker Assessment Tool for Lingual Frenulum Function (ATLFF). There are many of these scoring assessments. This gives objective information to help the examiner decide whether a tongue-tie or lip-tie release should be considered or not for that baby.
Most babies tolerate the examination very well.

The Tongue-Tie Team

Evidence-based tongue-tie research supports a multidisciplinary team approach and early intervention for the best outcomes for babies. Below are some members of a typical team. They may be part of a dedicated clinic or work separately.

Lactation Consultant

A lactation consultant is a feeding specialist and has expert knowledge in infant feeding, including breast and oral anatomy. They can guide parents towards optimal outcomes when a tongue-tie is diagnosed from pre- to post-tongue-tie release. The lactation consultant works with the breastfeeding mother and baby by identifying feeding challenges and formulating and individualized care plan.

Osteopaths, Physiotherapists or Craniosacral Therapists can assess your baby's body for any areas of strain that may be contributing to feeding issues associated with a tongue tie.

When a baby is born, their skull is made up of soft, bony plates that haven't yet fused together. During a birth, particularly one requiring intervention, or during the baby's growth in the womb, some compression of these bones can occur. This compression within the skull can result in tension within the bones, joints and connective tissue of the head, face and neck. These areas are all intricately involved in the biomechanics of infant feeding at either the breast or bottle.

Torticollis (the tightening of muscles on one side of the neck), a head turning preference, and neck and jaw tension are all commonly involved in feeding and latch issues. A baby with these strains may have difficulty extending the upper neck well enough or opening the jaw wide enough to allow a deep latch, or may prefer to feed from one breast over the other when they have a head turning preference.

In babies with a tongue tie, the tension in the mouth created from a tie may further complicate these strain patterns throughout the body. Babies with tongue-tie will often have overworked other parts of their body in order to compensate for a lack of movement in the tongue itself.

These areas of tension, strain and compensation can be addressed by experienced professionals using gentle hands-on therapy.

There is little evidence supporting the use of manual therapy to address infant feeding issues. However, the practice is anecdotally widely used and well tolerated.

Feeding Therapist

Babies with tongue-tie can sometimes experience disorganized suck, or have a weak or over-developed tongue, cheek or lips. They may have their mouth open at rest or when asleep. Sometimes these problems persist even after a tongue-tie release and are best managed by a feeding specialist. A feeding specialist is generally a speech and language therapist. They have a role in assessing and identifying and treating any oral motor deficits (the ways in which the mouth functions). This therapy can be used before and after a tongue-tie release. Sometimes this therapy is called oral motor therapy or oromyofunctional therapy. However, not every baby requires specific feeding therapy. Unfortunately, in Ireland, a therapist training in this type of work is rare. It is best to check with your nurse, midwife, GP or lactation consultant to see if this service is advisable and

available in your area.

Release-Provider

This is the professional that will perform the procedure. They can be a doctor, dentist, nurse or lactation consultant who has trained specifically in the area of tongue-tie and tongue-tie division. There is no formal training pathway for tongue-tie division in Ireland.

Treatment of Tongue-Tie

Tongue-tie management should be team-led and individualized and may include any of all of the following: feeding techniques, lactation input, bodywork, feeding therapy and tongue-tie release. Tongue-tie release is not a magic bullet and is only part of an overall plan to improve function. It can take several weeks to see the full effects of the release, as compensations ease, the tongue moves more, strengthens and sucking and swallowing become more co-ordinated.

A tongue-tie release, also known as the frenotomy, is the treatment for tongue-tie. For infants less than 4-6 months, it is performed using sterile instruments like scissors, or using diode or CO2 laser, or less commonly an Erbium or YAG laser. Infants less than 5 or 6 months tolerate the procedure without the need for sedation or general anaesthesia. Sometimes, depending on a child's temperament and the presence of teeth, this type of procedure can be performed up to 9 months. Sometimes, especially for older infants or revision procedures, oral sedation or general anaesthesia is used, and sometimes stitches are placed – this is known as a frenuloplasty. The majority of providers in Ireland use scissors. Scissors has the advantage of being quick and can create a few drops of blood in the baby's mouth, where as the laser takes a few seconds longer, but is thought to numb the area, and usually creates less bleeding. There is very little research to suggest which method is best.

Before the procedure

It is ideal that you do not feed your baby for up to 1 hour before your appointment since it is ideal that your baby to feed immediately after the procedure. If your baby becomes very distressed due to hunger, give him/her a small amount of milk in order to settle them, but not a full feed.

During the procedure

- A numbing gel is usually applied to the area.
- The procedure involves separating the tongue-tie using a sterile instrument. The head is then held still by a parent, nurse or other helper. Sometimes there are a few drops of blood. The whole procedure only takes a few minutes.

After the procedure

- Immediately after the procedure its ideal to try and feed your baby. Feeding immediately after the procedure is important since it provides comfort and pain relief, but also reduces bleeding

by applying pressure to the wound and protects against the very small risk of infection.

- Immediately following the procedure some mothers report a significant improvement in breastfeeding. For some mothers this improvement will take several feeds and indeed weeks, and sometimes bodywork or feeding therapy, with the baby having to adjust their feeding technique with a more mobile tongue.
- Unfortunately, for a small proportion of mothers there may be no improvement in feeding. This is often when there are other factors affecting the infant's ability to feed effectively, and this is why is it so important to seek out lactation support if breastfeeding prior to tongue-tie release.
- A small white/yellow diamond often appears beneath the tongue within 24 hours of the procedure. This is part of the normal healing process, and will disappear in a few days to weeks.
- Your baby's normal routine should be followed, with regular feeds, on demand.

Effectiveness of tongue-tie release

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.

Since then, there is emerging evidence that tongue-tie release can help with not only feeding issues but sleep and speech issues. However, more evidence is needed to ensure best practice and standardized care.

Potential risks

Reattachment: This simply refers to the release area under the tongue healing in a way that is tight and restrictive and is the most common potential risk of tongue-tie release. Incidence rates are quoted as anywhere between 4 and 20%.

There is debate on how or why this happens. The body wants to heal itself to it's original state, before any release, and the healing process starts to happen as soon as the procedure is done, so significant reattachment can occur within the first 24 hours after the release.

Pain: there are no studies that directly address pain and tongue-tie release. Some babies are sleep through the procedure and others cry. This may be due to the fact that the tongue is stretched during the procedure or that they do not like to be swaddled. Babies can be fussy after the procedure, especially days 2-5. Simple measures like skin to skin, soft music, singing to your baby, frequent feeds and vibration can really help. If your baby is over 4 KG, they can have calpol (paracetamol) as directed and prescribed by a doctor.

Bleeding: On occasions bleeding can occur, usually on the same day, when the babies have returned home (less than one in 300 babies). If this occurs the bleeding is usually very light and is triggered by strenuous crying (resulting in the tongue lifting and disturbing the wound) or when the wound is disturbed during feeding, particularly if the wound is caught by a bottle teat or tip of a nipple shield. 99.9% of of the time, this settles with a feed, or sucking on a finger or a pacifier. The risk of continued bleeding is 1 in 10,000 and requires hospital assessment.

Temporary refusal to latch: If your baby won't latch, don't worry. Hand expression is an especially useful tool for moments like this. Get skin to skin in a calm, quiet environment with dimmed lights. Express into the baby's mouth, or a syringe bottle or sterile cup. Attempt latching again when both

of you are calm. Expressing some breastmilk and freezing a breastmilk bag flat so that you can make small breastmilk chips can really help settle baby.
So, picking an alternative method prior to assessment can help, just in case. Here's some information on safely syringe or cup feeding your baby https://what0-18.nhs.uk/application/files/5515/9006/2049/Syringe_and_cup_feeding_your_baby_-_HT.pdf. If you're breastfeeding, try hand expression https://kellymom.com/bf/pumpingmoms/pumping/hand-expression/ . If you're using bottles, try paced bottle-feeding https://www.youtube.com/watch?v=GNMm4Twhvbs. Bottle-fed babies will very often struggle with the flow of a bottle, and using a small teat with paced feeds can really help allow a baby more control over the pace at which they drink.

Damage to surrounding structures like blood vessels or salivary glands, Syncopal (fainting), or reaction to numbing gel are rare complications.

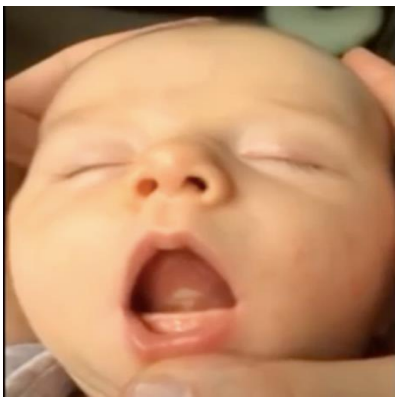
Aftercare of tongue-tie

Aftercare is highly variable in Ireland. It may consist of continued lactation support, ongoing bodywork, or input from other healthcare professionals.

There are different types of aftercare that may be recommended. Some of these are set out below:

Oral Motor exercises: These exercises aim to increase the tongue's movement, to strengthen the muscles involved in feeding and to co-ordinate the suck-swallow-breathe reflex involved in feeding. A feeding therapist can be involved in this part of aftercare.

Wound Management: When a release is fully divided, there is often a diamond shape under the tongue. It is thought that perhaps the edges of this new diamond join back together. The aim of wound management is to prevent reattachment, and involves lifting and/or massaging the tongue in order to keep the diamond open, while new tissue heals at the base of the diamond. Currently, there is no research comparing reattachment rates in babies where wound management was done versus no wound management. The use of wound management is commonplace in the United States, but the frequency and types of stretches is variable.



In addition to wound management, frequent feeding, a deep latch, bodywork, pain management, tummy time, and tongue stretches while the baby is sleeping and avoidance of bottles and pacifiers are thought to reduce reattachment rates.

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