**My Baby has a Tongue-Tie: Should I Have it Released?**

A decision aid to discuss options with your health care team

**This decision aid is for you if:**

* You are concerned your child has a tongue tie or your child was diagnosed with a tongue- tie
* You are experiencing pain while breast or chest feeding, or your child is having feeding problems
* Your health care team thinks a tongue-tie release procedure may help
* This decision aid is for parents of children less than 12 months of age

**What is a tongue tie (ankyloglossia)?**

A tongue tie, or ankyloglossia is when the tongue attachment (lingual frenulum) to the floor of the mouth is short and restricts movement of the tongue. A child may be born with a tongue tie, and it may impact breast or chest feeding by interfering with achieving a deep latch and milk transfer. It may also cause the parent pain while breast or chest feeding.

**What is a tongue-tie release?**

A tongue tie release is a procedure that is done to release the lingual frenulum to allow for more range of motion of the tongue. Providers that can perform this procedure include ENT/otolaryngologists, dentists, oral surgeons, and some pediatricians.

There are a few procedures that can be done:

* **Frenotomy or frenectomy:** the provider may cut the lingual frenulum using scissors or a scalpel
* **Laser frenectomy:** cutting of the lingual frenulum by using a CO2 or diode laser; usually done by a pediatric dentist
* **Frenuloplasty:** Involves surgically repositioning the tissue and placing stitches

Depending on the setting, a tongue-tie release may be done with or without general anesthesia.

**What are your options?**

|  |  |
| --- | --- |
| ¨ | **Conservative measures:**   * Meet with a lactation consultant (IBCLC) to evaluate feeding and improve latch with positioning and other interventions. * Meet with feeding therapist (speech language pathologist or occupational feeding therapist) to evaluate oral function * Alternate feeding methods such a bottle feeding * Alternative treatments (discuss with your healthcare provider) |
| ¨ | **Pursue a tongue tie release with an experienced provider**   * Some providers offer a tongue tie release while the child is awake **without anesthesia**   + May be a frenotomy, frenectomy, CO2 laser or diode laser frenectomy   + Typically, no stitches are used * Some providers offer a tongue tie release while the child is asleep **with general anesthesia**   + May be a frenectomy or a frenuloplasty   + Typically, stitches are placed under the tongue when this procedure is done under anesthesia |
| ¨ | **Decline tongue tie release and discuss other options with your health care provider** |

**What other health factors may affect your choice?**

Check R any that apply and discuss your concerns with your HCP.

|  |  |
| --- | --- |
| **£** Breast or nipple pain  **£** Baby has poor growth | **£** Baby has another health condition  **£** Other |
| **£ None** of these apply to me | |

**Working through the 4 steps of this decision aid may help you consider the options.**

**Step 1: What are the benefits and harms of each option?**

**What does the research show?**

While research in this area is limited, available evidence shows that performing a tongue tie procedure when parent is experiencing breast or nipple pain while breastfeeding may reduce the parent’s pain. A tongue tie release may also improve infant feeding behaviors.

There is little research to recommend a preferred release procedure or timing of procedure. There is also little evidence to predict long-term effects of not doing a procedure.

**Benefits:**

* Reduce parents’ breast or nipple pain
* Parents report improvement in feeding after tongue tie release

**A tongue tie release is usually a safe procedure, but any procedure carries risks.**

**Risks:**

* Bleeding
* Infection
* Need for re-operation
* Risks of anesthesia if performed under anesthesia
* No improvement in symptoms
* Rare complications such as lip injury, injury to salivary gland, breathing issues
* Available evidence shows comparable risks across treatment types (Frenectomy, frenotomy, frenuloplasty and CO2/diode laser procedures)

Blocks of 100 faces show a ‘best estimate’ of what happens to **100 people** with a tongue tie who undergo a tongue tie release. Each face (K ) stands for one person. The shaded areas show the number of people affected. There is no way of knowing in advance if your child will be affected.

|  |  |
| --- | --- |
|  |  |
| **Benefits [+++]** | **Tongue-Tie Release** |
| When a child undergoes a tongue tie release, **56 parents report improved feeding outcomes** | **56 have improved feeding outcomes**, 44 do not have improved feeding outcomes  KKKKKKKKKK  KKKKKKKKKK  KKKKKKKKKK  KKKKKKKKKK  KKKKKKKKKK  KKKKKKKKKK  KKKKKKKKKK  KKKKKKKKKK  KKKKKKKKKK  KKKKKKKKKK |
| If the child undergoes a tongue tie release,  **88** **people may get** **improvement in**  **parent breast or nipple pain** | **88 parents have improved pain,**  12 do not have improvement  KKKKKKKKKK  KKKKKKKKKK  KKKKKKKKKK  KKKKKKKKKK  KKKKKKKKKK  KKKKKKKKKK  KKKKKKKKKK  KKKKKKKKKK  KKKKKKKKKK  KKKKKKKKKK |
| **Minor Harms [++]** |  |
| If the child undergoes frenotomy or laser procedure, 6 people may need a repeat procedure | **6 may need repeat procedure**, 94avoid this  KKKKKKKKKK  KKKKKKKKKK  KKKKKKKKKK  KKKKKKKKKK  KKKKKKKKKK  KKKKKKKKKK  KKKKKKKKKK  KKKKKKKKKK  KKKKKKKKKK  KKKKKKKKKK |
|  |  |
| When a child undergoes a frenotomy procedure, **32 may have minor bleeding** | **32 will have minor bleeding**, 68 avoid this  KKKKKKKKKK  KKKKKKKKKK  KKKKKKKKKK  KKKKKKKKKK  KKKKKKKKKK  KKKKKKKKKK  KKKKKKKKKK  KKKKKKKKKK  KKKKKKKKKK  KKKKKKKKKK |

Note: The options include ‘estimates’ of what happens to groups of people based on the available research. The quality of these estimates is rated using the GRADE system as follows: ++++ **High** quality – further research is **very unlikely to change** the estimate; +++ **Moderate** quality – further research **may change** the estimate; ++ **Low** quality – further research is **likely to change** the estimate; + **Very low** quality – further research is **very likely to change** the estimate.

# Step 2. What matters most to you?

Common reasons to choose each option are listed below.   
Check ü how much each reason matters **to you** on a scale from 0 to 5.   
**‘0’** means it is **not** important to you. **‘5’** means it is **very** important to you*.*

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
|  | Reasons to **have your child undergo a tongue tie release:** | **Not Important** | | | **Very**  **Important** | | |
|  | How important is it to you that your child has the tongue tie procedure done? | i | j | k | l | m | n |
|  | How important is it to you to breastfeed your child? | i | j | k | l | m | n |
|  | How important is it for you to resolve the current symptoms you or your baby are experiencing? | i | j | k | l | m | n |
|  | Reasons to decline **tongue tie release?** | **Not Important** | | | **Very**  **Important** | | |
|  | How important is it to you to avoid side effects of procedure? | i | j | k | l | m | n |
|  | How important is it for you to avoid costs associated with the procedure? | i | j | k | l | m | n |
|  | How important is it that undergoing a procedure improves you and your baby’s symptoms? | i | j | k | l | m | n |

**Step 3: What else do you need to prepare for decision making?**

|  |  |
| --- | --- |
|  | **Find out how well this decision aid helped you learn the key facts.** |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Check R the best answer. | **[A]**  **Tongue- Tie Release** | **[B] Conservative Measures** | **[C]**  **Both same** | **[D]**  **Don’t know** |
| **1.** | Which option has the highest chance of **reducing parent’s pain during breast or chest feeding** if your child has a tongue tie? | **£** | **£** | **£** | **£** |
| **2.** | Which option has the lowest chance of leading to **no improvement of symptoms**? | **£** | **£** | **£** | **£** |
| **3.** | Which option has the highest chance of **bleeding or infection**? | **£** | **£** | **£** | **£** |

Answers for the key facts: 1. [A], 2. [C], 3. [A].

**Now, think about which option has the reasons that are most important to you…**

**Which option do you prefer?** Check R one.

**£** Do nothing

**£** Conservative measures: evaluation by skilled lactation consultant, occupational feeding therapist, discuss alternative treatments with your health care provider

**£** Pursue a tongue tie release procedure

**£** I don’t know

**£** Something else

# Step 4: What are the next steps?

Check R what you want to do next.

**£**  I have decided to have a tongue tie release for my child.

**£**  I have decided to decline a tongue tie release for my child.

**£**  I have decided to go with conservative or alternate treatments for my child.

**£**  I need to discuss the options with my health care provider and family.

**£** I need to read more about my options.

**£** Other, please specify

**This information is not intended to replace the advice of a health care provider.**

Last reviewed: 1-25-24.

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Funded in part by: All Authors have declared no conflict of interest. Format based on the Ottawa Personal Decision Guide © 2000, A O’Connor, D Stacey, University of Ottawa, Canada. For more information, contact Sally Danto, RN, MSN, PNP-PC, IBCLC, [sdanto@chla.usc.edu](mailto:sdanto@chla.usc.edu), 323-361-7101, 4650 W. Sunset Blvd, Los Angeles, CA, 90027. Benefits and harms data take from Khan, U., MacPherson, J., Bezuhly, M. & Hong, P. (2020). Comparison of frenotomy techniques for the treatment of ankyloglossia in children: A systematic review. *Otolaryngology- Head and Neck Surgery, 163*(3), 428-443.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Find out how comfortable you feel about deciding.** | | | | | |
|  | **Strongly Agree** | **Agree** | **Neither Agree or Disagree** | **Disagree** | **Strongly Disagree** |
| 1. I know which options are available to me. | **ÿ** | **ÿ** | **ÿ** | **ÿ** | **ÿ** |
| 1. I know the benefits of each option. | **ÿ** | **ÿ** | **ÿ** | **ÿ** | **ÿ** |
| 1. I know the risks and side effects of each option. | **ÿ** | **ÿ** | **ÿ** | **ÿ** | **ÿ** |
| 1. I am clear about which benefits matter most to me. | **ÿ** | **ÿ** | **ÿ** | **ÿ** | **ÿ** |
| 1. I am clear about which risks and side effects matter most. | **ÿ** | **ÿ** | **ÿ** | **ÿ** | **ÿ** |
| 1. I am clear about which is more important to me (the benefits or the risks and side effects). | **ÿ** | **ÿ** | **ÿ** | **ÿ** | **ÿ** |
| 1. I have enough support from others to make a choice. | **ÿ** | **ÿ** | **ÿ** | **ÿ** | **ÿ** |
| 1. I am choosing without pressure from others. | **ÿ** | **ÿ** | **ÿ** | **ÿ** | **ÿ** |
| 1. I have enough advice to make a choice. | **ÿ** | **ÿ** | **ÿ** | **ÿ** | **ÿ** |
| 1. I am clear about the best choice for me. | **ÿ** | **ÿ** | **ÿ** | **ÿ** | **ÿ** |
| 1. I feel sure about what to choose. | **ÿ** | **ÿ** | **ÿ** | **ÿ** | **ÿ** |
| 1. This decision is easy for me to make. | **ÿ** | **ÿ** | **ÿ** | **ÿ** | **ÿ** |
| 1. I feel I have made an informed choice. | **ÿ** | **ÿ** | **ÿ** | **ÿ** | **ÿ** |
| 1. My decision shows what is important to me. | **ÿ** | **ÿ** | **ÿ** | **ÿ** | **ÿ** |
| 1. I expect to stick with my decision. | **ÿ** | **ÿ** | **ÿ** | **ÿ** | **ÿ** |
| 1. I am satisfied with my decision. | **ÿ** | **ÿ** | **ÿ** | **ÿ** | **ÿ** |

If you did not answer ‘Strongly Agree’ or ‘Agree’ to any of these, discuss with your health care provider. (Decisional Conflict Scale, AM O’Connor, 1993)