JENNY LIND CHILDREN'S HOSPITAL

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Jenny Lind Children's Hospital
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Information for Parents / Carers of a Baby referred with a Suspected Restrictive Lingual Frenulum (Tongue-Tie)

Dear Parents / Carers

Your baby has been referred for assessment of tongue mobility and a possible division of lingual frenulum (tongue tie). This leaflet will help you prepare yourself for this consultation and procedure (if required) and answer some of the questions you may have since about the referral. **Please read this information sheet before your appointment as it includes important information.**

Why has my baby been referred to a specialist?

Your baby is having problems with feeding or symptoms which suggest ineffective feeding. These may be due to a restriction of tongue movement, as a result of which, your baby may be unable to make an effective attachment to the breast or bottle. The referrer should have already ruled out difficulties due to positioning your baby for feeding.

Referrals for bottle fed babies with feeding issues (that have tried different teats) or babies with problems eating solid foods may be accepted.

Do I need to restrict babies feeding prior to the appointment?

Yes, we require your baby to be hungry at the appointment so request that you do not feed your baby for approximately 2 hours prior to the appointment time to ensure they will feed afterwards. This is important as it helps to reduce and stop any bleeding. It is possible that you may have to wait sometime in the waiting room so your baby may feel very hungry just prior to the appointment. Although upsetting for parents, this is helpful during assessment of tongue movements and will help your baby to be interested in feeding after the procedure. You can offer your baby a clean finger to suck to keep them as settled as possible whilst you are waiting. Unfortunately, we cannot guarantee that you and your baby will be seen exactly at the appointment time.

Can both parents attend with baby?

Yes, both parents/carers can attend with baby however we ask you to limit the number to two as other paediatric and neonatal clinics run alongside the RLF clinic. Please bring a pram or have your baby in a sling to protect your back from carrying baby in a car seat. We recommend that someone brings you the reason for this is to ensure that they can support you and your baby after the procedure. If a frenulotomy is performed, you can safely drive/be driven home without being distracted, and you can also be supported if you use public transport.

What will happen at the time of the consultation with the specialist midwife/nurse/doctor?

The specialist midwife/nurse/doctor will examine your baby and thoroughly discuss the pros and cons of the condition, if present, and the options including division of frenulum (tongue-tie). The procedure may not be offered if the tongue movements are noted to be normal and if the doctor /specialist midwife/nurse doesn't see a benefit to your baby of performing the procedure. Either way, the decision is taken after an informed discussion and your signature will be required as written consent. We will ensure you are aware of the risks of the procedure which are:

- Excessive bleeding requiring intervention (approx. 1 in 1000 babies).
- Infection of the wound (extremely rare).
- Damage to the floor of the mouth (extremely rare).
- Pain for your baby (equal to or less than routine vaccinations for almost all babies).

During the assessment and procedure, your baby is gently and carefully wrapped in a blanket, so please bring one with you. At this stage the movements of baby's tongue are assessed and if restricted, the doctor or specialist midwife/nurse will offer to divide the tissue found below the tongue (the frenulum) using sterile scissors. We use expressed breastmilk if possible, or sucrose (sugar water) solution to elicit tongue mobility and to act as pain relief prior to the procedure. Breastmilk (1-2ml) can be used and has been shown in research studies to be as effective as sucrose for pain relief. If you are able to, please bring a syringe/container of 1-2ml of breastmilk. There is no anaesthetic given to baby but the majority of babies tolerate this procedure extremely well.

Most parents have reported that the distress to their baby has been minimal and in most circumstances less than the distress at the time of immunisation injections.

We will ask a nurse/midwife to hold your baby still on the examination bed during the assessment and procedure unless you would like to hold them, please say if you would like to hold your baby.
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Immediately after the division procedure, you will be asked to put your baby to your breast/ offer a bottle. Babies usually feed normally after the division and do not behave as if they are distressed or upset. It is believed that the milk will soothe the small cut under the tongue. If you are currently struggling to breastfeed and your baby has been bottle feeding expressed breastmilk instead, please bring nipple shields with you so we can help to try and transition your baby back to breastfeeding.

Immediately after the procedure, baby is encouraged to feed.

We expect babies to cry during assessment. The cry may become a little louder for a few seconds or up to a minute following division but the baby is expected to settle down quickly with feeds. In rare circumstances, the cry may take a couple of minutes to settle. If you believe that you will feel upset about this, you may discuss this with the doctor or specialist midwife/nurse and opt to stay outside the clinic room.

The feeding is interrupted after a couple of minutes to check for any bleeding. In rare circumstances, if there is still some bleeding, the doctor/specialist midwife/nurse may take the baby back to the examination table and place some pressure with a small dressing at the site of the cut for 5 minutes at a time (sometimes more than once). This is needed rarely (approximately 1 case in 1,000) but you do not need to worry as your baby is in a safe environment and the doctor/specialist midwife/nurse performing the procedure is well trained to manage this situation. We always have the support of the surgical team if required.

Once the doctor/specialist midwife /nurse is satisfied with your baby, you will be asked to sit outside the clinic room with your baby or in some cases can go straight home. A final check is made and at this stage the doctor/specialist midwife/nurse will explain what to expect in the next few days.

Will my baby be given an anaesthetic or sedation?

No, we do not use any sedation or General Anaesthetic during the assessment and/or procedure. (General Anaesthesia may cause higher levels of distress during the process with added potential risks and complications). Giving local injections are more distressing. Applying local anaesthetic or using sedation has not been shown to be beneficial. As the level of distress is so low in the majority of babies, and equal to or less than routine vaccinations, it is considered appropriate to perform this procedure without anaesthesia or sedation in small babies.

Summary of what to bring with you to your baby’s appointment

- A blanket or large muslin to wrap your baby in.
- Some expressed breastmilk (2mLs ideally) if you can. We can provide syringes if needed.
- Your baby’s Child Health Record (red book).
- The consent form to sign to enable us to perform the frenulotomy if needed. If you do not have a printer, we can provide a copy.
- A note of any questions you or your partner may have.

Why is Vitamin K important prior to the procedure?

Vitamin K helps the blood to clot and prevent serious bleeding. In newborns, giving Vitamin K can prevent a rare but fatal bleeding condition called “Vitamin K deficiency bleeding” or “Haemorrhagic disease of the newborn”. If your baby has not received intramuscular (IM) injection of Vitamin K or alternatively, at least 2 doses of oral Vitamin K, please contact the RLF team before the appointment so that we can discuss this with you.

Aftercare- How will my baby react once we have returned home?

Most parents report that their baby reacts no differently than before. All babies are different however, and some may need more comfort and reassurance. Skin to skin contact co-bathing, baby wearing using a sling and offering frequent feeds will help.

How will the wound look and how long will it take to heal?

Healing starts very quickly at the site of the division. In the first few days, you will notice a

whitish / grey colour at the site of the cut (which is diamond shaped). This will change to a yellow colour in approximately a week's time and finally heal leaving a small string like appearance. This is normal and not a recurrence. Very rarely a small yellow blister may be noted at the site of the cut. This heals up quickly. If you remain concerned, please discuss with a health care professional.

We recommend that for the first 48 hours after division you cover your baby's hands with mittens/their Babygro to prevent them touching the wound with their fingers and making it bleed. You do not need to do any wound massage or stretching exercises as there is no current evidence that these are beneficial and some concerns that they may actually be harmful. They can lead to oral aversion in babies. The type of divisions offered at our hospital mean that a full and complete division is performed to achieve a "diamond shaped" wound. On rare occasions there may be some babies who develop wound healing with scar tissue formation after two weeks.

Although there are reports suggesting reattachment can cause recurrence of restriction, the majority of this is due to the scar formation. If the division is complete with a diamond shaped wound during the first division, it is unlikely that a further division would be helpful as yet more scar tissue could form. For this reason we do not usually encourage a second division. In addition, subsequent divisions have a higher risk of bleeding, more scar tissue and pain for the baby.

Lip Tie

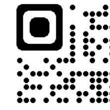
There is no current published evidence supporting a link between breastfeeding problems and lip tie. Although the lip provides a good seal around the nipple and areola, the process of sucking is mainly between the tongue and the palate. The National Institute for Health and Care Excellence (NICE) have not issued any guidance on this issue. **The only indication to do any intervention would be dentition issues in the future, after the eruption of adult teeth** and on the referral from a dentist. If you require further information please call 01603 286307.

Follow up support arrangements

Feeding support from IBCLC Lactation Consultants and/or the community NHS teams is very important after your appointment. The health professional / IBCLC breastfeeding supporter who referred your baby to the RLF team, will offer follow-up support and / or arrange a colleague to provide feeding support. Please ensure you know how to contact such support. A list of support groups in Norfolk is available on our Maternity Unit's infant feeding Facebook page, "NNUH Infant Feeding" and also on our department webpage:

http://www.nnuh.nhs.uk/departments/maternity-department/feeding-and-caring-for-your-baby/support-groups/. In addition you can access information about feeding support from your Health Visiting Team www.Justonenorfolk.nhs.uk. If you live outside of Norfolk please ensure you get local help and support following your appointment. Please remember it often takes 2 weeks to see a full improvement in feeding and in some rare cases, even longer.

Feedback and Comments

You are requested to provide us with feedback of your  experience with the service. Participation is voluntary and all responses are anonymous, if you decide not to participate, this will not affect the care you receive from the service. Please use the QR code/link to the feedback form approximately 2 weeks after the procedure. This is very important as this is the only way we know whether the procedure was of any help to your baby and to pick up any concerns. This helps us to improve our service and guide parents in similar situations. Above all, this is your significant contribution towards the wellbeing of our future generations.

The directions to the Jenny Lind Children's Hospital are as follows:

- The Postcode for the Norfolk & Norwich University Hospital is - NR4 7UY.

- If you are arriving by car, at the hospital roundabout follow the signs for Outpatients. The closest car parks are D and C. Please enter the hospital via the **Outpatients West Entrance, Level 2** and turn left by the coffee bar. The Jenny Lind Children's Hospital is situated along this corridor on the right-hand side.

- Should you have any queries please talk to one of our Receptionists.

Should you have any concerns please contact our RLF co-ordinator on 01603 286307 or email on RLFservice@nnuh.nhs.uk

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