Huge variation in NHS infant tongue-tie services

Surgery to relieve tongue-tie in babies is simple and effective and yet in many areas there is little or no provision for diagnosis, treatment or support, sometimes resulting in severe feeding difficulties. Patricia Wise, breastfeeding counsellor and NCT tutor, reveals the findings of a recent NCT survey of NHS infant feeding leads

In 2014, following an enquiry from the BBC to NCT about tongue-tie and then a request for parents to write to NCT about their experiences, it became very apparent that some UK parents were very dissatisfied because of a lack of availability of a tongue-tie division service for their baby. The NCT Press Office collected 30 stories from parents and these mentioned a lack of NHS support, no services in some areas and women stopping breastfeeding before they wanted to due to feeding problems. NCT wrote to the then Health Minister, Dan Poulter, and a parliamentary question was also asked. NCT members were encouraged to write to their MPs calling for better services.
It seemed sensible to me to obtain a clearer picture of the actual provision of such services and a small working group led by Senior Policy Adviser, Rosie Dodds, and including Head of Research, Sarah McMullen compiled a set of SurveyMonkey questions to send to infant feeding leads in the NHS.

**Tongue-tie effects on baby and mother**

A tongue-tie occurs when there is tightness in the cord-like membrane (frenulum) under the tongue. This is only significant if it affects how the tongue functions so, if a baby with a tongue-tie is feeding well, no action is needed. Some babies can have a very noticeable tongue-tie (called anterior) yet manage to feed well enough, while others can have a scarcely visible tongue-tie (called posterior) and feeding may be severely affected. In more noticeable cases, where the frenulum is attached at or near the tip of the tongue, the tongue often does not protrude beyond the lower lip and can look heart-shaped. Some babies with a tongue-tie suck more strongly, presumably to compensate for the restricted tongue movement.

Studies indicate that up to one in ten babies has a tongue-tie but maybe half of those manage to feed satisfactorily. Babies who are breastfeeding are more likely to be affected and have difficulty with attaching well to the breast but some struggle with feeding from a bottle; feeds can take a long time, with milk dribbling from the baby’s mouth. If a mother has painful, damaged nipples it is very likely that the baby is not attached well enough at the breast. A baby who is not obtaining enough milk may need more frequent feeds or better attachment. It is therefore crucial that any mother who is having difficulty with breastfeeding receives skilled help. Sometimes, even with a tongue-tie, improvements to the baby’s attachment at the breast are enough for feeding to become effective. Thus, only if other factors have been addressed and excluded first can a baby be assessed as having a tongue-tie affecting feeding. While there is concern about under-diagnosis of tongue-tie, there is also concern about over-diagnosis, in situations where tongue-tie is assumed to be the cause of difficult breastfeeding without skilled help being given first.

The division procedure is quick — cutting the frenulum with scissors to release the tightness. The risk of not dividing a tongue-tie that has been assessed as affecting breastfeeding is that the mother is more likely to stop breastfeeding early.

When Emma’s baby Theodore was born he was unable to attach to the breast, despite help from midwives. He was described as having a severe tongue-tie, which was divided in the hospital at one day old. He then managed to attach but only shallowly so needed top-ups of expressed milk and formula. Emma was convinced he still had a tongue-tie and eventually, when Theodore was six weeks old, his tongue-tie was divided at a community NHS clinic. However, he then refused to attach. After eight days he suddenly did attach and at last he could feed well. Emma was able to have the experience of her baby breastfeeding that she had longed for, although she did then suffer three bouts of engorgement!
What is the evidence that surgery can help?

Ten years ago, NICE (National Institute for Health and Care Excellence) stated that tongue-tie division is a safe procedure that may help breastfeeding. Since then more studies have been done, including some involving randomising babies to a sham procedure first to try to eliminate the placebo effect. Double-blind randomised trials would be hard to organise as mothers may be reluctant to be in a control group and can often identify whether their baby has had a division.

Edmunds et al reviewed the literature in 2011, confirming that tongue-tie can negatively affect breastfeeding for babies and mothers and that division is a simple, safe and effective procedure. There have been five randomised controlled trials, which all show an improvement in mothers’ experiences of breastfeeding. Hogan et al used single blinding and mothers in the intervention group reported significant improvements in subjective experience compared with the control group. In Dollberg et al’s randomised crossover study, control group participants were initially given a sham procedure. There was a significant reduction in maternal pain scores in the intervention group and a non-significant improvement in latch. Buryk et al’s study involving a sham procedure showed that, although there was a placebo effect, there was a significantly greater reduction in maternal pain and improvement in latch in the frenulotomy group. Berry et al’s 2012 double-blind study found a significant improvement in mothers’ reported experience of breastfeeding following division. Emond et al’s study included only tongue-tie cases assessed as mild or moderate. There was a significant improvement in maternal self-efficacy — in effect confidence in being able to breastfeed. Use of the existing LATCH tool to assess breastfeeding did not show a significant improvement yet the qualitative interviews indicated mothers tended to experience relief from painful feeding. This suggests that the LATCH tool was not sensitive enough.

In all the studies, division was offered for babies in the control group within five days of the intervention group so it is not possible to demonstrate differences in breastfeeding duration between the intervention and control groups. Also, different methods of assessment were used and there is limited evidence about which babies are most likely to benefit from division.
Survey findings
The link to the survey was passed on by Francesca Entwistle, coordinator of NIFN, the National Infant Feeding Network, to the regional infant feeding leads, who in turn sent it to the local leads. Fifty one per cent of NHS Trusts (England and Northern Ireland) and Boards (Scotland and Wales) were represented in the responses, which showed that, in this snapshot, at least 42% of all the Trusts and Boards do have a service and at least 10% do not. The findings confirmed what was suspected — the huge variation in the services provided:

• mainly hospital-based but some community-based
• some commissioned, some not
• some providing a service for bottle-fed babies, some not
• some accepting referrals for posterior tongue-ties, some not
• some accepting out-of-area referrals, some not
• variation in the divisions as a percentage of new births in an area from less than 1% to 7%
• variation in the waiting times for division, with 10% waiting for more than 3 weeks
• variation in the maximum age for referrals from one to two months to no limit
• may be run by midwives, ENT surgeons, maxillofacial surgeons, dentists or paediatricians
• variability in the quality of assessment
• breastfeeding support is not always available immediately after division and follow-up is variable

Several barriers to setting up a service were mentioned, including funding, staffing, lack of training and the need for a suitable venue. In some cases, differences in clinical opinion was mentioned as an issue, despite the 2005 NICE guidance, resulting in disagreement on the need for a service.

Report recommendations
1. All Trusts/Boards work towards or maintain Baby Friendly status, to provide adequate skilled breastfeeding support.
2. If needed, parents have easy access to a tongue-tie service.
3. Services have sufficient capacity.
4. Identify priorities for further research.
5. Review the training process, particularly for quality control.
6. All who work with mothers and babies recognise tongue-tie division can be beneficial.
7. Agree good practice protocols.
What can practitioners do?

1. Where the opportunity arises, convey accurate messages about infant tongue-tie:
   - no action is needed unless feeding is affected
   - skilled help is needed to assess whether division of a tongue-tie is likely to improve feeding.
2. If a mother’s breastfeeding experience is unsatisfactory, signpost her to skilled breastfeeding help.
3. If there is no assessment and division service locally, or the service is unsatisfactory, raise awareness in a forum such as an MSLC or with the Head of Midwifery or local commissioner.

References


Further Information
