healthwatch Cambridgeshire

healthwatch Peterborough

Making local Tongue Tie Services Work for New Parents and Babies

Tongue Tie (Ankyloglossia) services in Cambridgeshire are inadequate and overly complicated, according to families, professionals, and mothers trying to breastfeed a tongue tied infant. Healthwatch Cambridgeshire has been contacted by mothers or other family mothers wishing to share their experiences struggling with tongue tie. We have spoken to midwives, health visitors, and lactation consultants who are frustrated by the lack of support available for women trying to feed a tongue-tied baby. We have also been contacted by Lucy Frazer, MP for South East Cambridgeshire, regarding concerns she has heard about tongue tie services.

We would like tongue tie services to be reviewed, in order to improve:

- Assessment
- Information provision
- Referral pathways
- Equal access to services regardless of income or geography

The following information is based primarily on experiences that were shared with Healthwatch Cambridgeshire. These stories are summarised below, but are available in greater detail. All but one of the stories refers to services at the Rosie and in or nearby the city of Cambridge. Within the stories shared with us, themes became apparent very quickly; these were backed up by the professionals. In the past several years, there have been reports on tongue tie services in both the national and local press that indicate the scale of the problem.

We collected this information in 2016, but this is not a new concern. Records of online petitions such as: https://www.ipetitions.com/petition/tongue-tie-cambs/ to improve tongue tie services in Cambridgeshire go back further in time. Many Cambridgeshire residents have shared their experiences in the comments section of that petition, as recently as February, 2017, but going back to 2013.

<u>Assessment</u>

Women told us about extraordinary pain as a result of trying to feed a tongue tied baby, both physical pain (swollen or bleeding nipples, plugged ducts, and agony when the baby tries to latch) as well as emotional distress due to baby not thriving or not feeling successful with breastfeeding, despite immense pressure to do so. Despite significant and similar symptoms, most of the women we talked to felt like tongue tie was missed by the first professionals who should have been able to assess the baby for tongue tie and advise families on how to proceed.

Women on the recovery ward at the Rosie were most likely to have tongue tie assessed when they asked to speak with the infant feeding specialist midwife. At the time, this was Jo Watt, a certified lactation consultant who was trained to provide tongue tie division, though she did not perform this service. She is credited by many women as having saved their ability to breastfeed. Jo Watt no longer works at the Rosie, and staff have told us that currently there is no practitioner with sufficient training to diagnose tongue tie.

In the community, mothers felt that midwives and health visitors were reluctant to speak about tongue tie. Most were referred to breastfeeding support groups. One mother was told by a community midwife that 'they (midwives) aren't telling people when they spot a tongue tie, due to lack of resource and wanting women to carry on breastfeeding'.

Breastfeeding support groups in Cambridge were generally described as helpful, and a turning point for many women. Even at the breastfeeding support groups, women were often told that the breastfeeding support workers couldn't diagnose tongue tie, though they could identify it as a possible cause of problems. The problems with referral for tongue tie services are addressed below.

Self-Assessment

Mothers and professionals told us that you are most likely to get help with tongue tie if you know it's a problem and ask for help. We spoke to women who were proactive in seeking out assessment and support as a result of an earlier child having tongue-tie, other family experience with tongue tie, or belonging to a group (for example, NCT groups) in which other new mothers have experience trying to feed a tongue- tied baby.

Many issued concern that, in the event that a new mother does not know about the problems tongue tie can cause, she will either suffer significant pain for longer than necessary and/or stop breastfeeding before she wants to. It is, of course, impossible to quantify how many women do not get support for an issue they don't know about.

A heavy reliance on self-referral may also be adding to inefficiencies for professionals. Early and accurate assessment for tongue tie allows mothers struggling to breastfeed because of a tongue tie to get timely support, but also allows mothers who are struggling to breastfeed for a reason unrelated to tongue tie the chance to pursue appropriate support as well.

Information provision

When tongue tie is discussed, women are hearing different things from different professionals.

This is particularly clear amongst women who stayed for days at the Rosie after giving birth. One woman was told that her nipples were deforming during feeds (a classic sign of tongue tie) because the baby was eating well, and that the pain she was experiencing was 'normal'.

We were also told about women being held on the Charles Wolfson ward, their babies not being discharged specifically because they had difficulty feeding. There was no lactation consultant on the Charles Wolfson ward, despite difficulty feeding being the primary reason for staying there. One mother requested an assessment from the Rosie's infant feeding specialist, who assessed her twin babies as having tongue tie and recommended that mother seek private care to have the tongue tie divided. She was then told by a consultant, "There is no evidence that tongue tie division will help your babies to feed." As her first child (born in 2011) was born with tongue tie, (the division of which was provided by the NHS in Bedford) the family opted to pay for private care. She is now successfully breastfeeding both babies.

We spoke with other women who reported feeling angry that they were told by a consultant that tongue tie division would not help them; however, when they sought private care and had the tongue tie divided, they experienced a reduction in pain and the babies all fed better.

We also spoke to women who were told that the baby was tongue tied shortly after birth, and advised to 'wait and see.' However, there was no clear information provided about what to expect, how to know if the tongue tie was interfering with feeding, or what to do if it did.

Tongue ties do not always need to be separated for mother and baby to have a successful breastfeeding relationship. We spoke to 2 women whose babies were assessed as tongue tied when they were born who, with the support of local community breastfeeding support groups, were able to breastfeed with minimal negative side effects. Unfortunately, the degree of tongue-tie does not determine whether or not there will be problems feeding. Support needs are not being met, because the fact that some women successfully feed a baby with tongue tie is being conflated with a message that tongue tie doesn't ever cause problems, or that division cannot help.

Referral pathways

For most of the women we spoke to, the pathway to tongue tie division was complicated. Usually, a health visitor, midwife, or friend referred them to a community breastfeeding support group, where a breastfeeding support worker or lactation consultant assessed with varying degrees of certainty the baby's tongue tie. The mother was then told to go to her GP for a referral to CUH (if the tongue tie is anterior) or Bedford or Norwich (if the tongue tie is posterior).

These mothers were warned about long waiting lists and the possibility that the GP may not provide the referral, as well as the possibility that CUH would refuse to perform a division that might be 'complicated'.

Having to make an appointment with a GP, who is not a lactation consultant, may not know anything about tongue tie, and/or may not agree that the tongue tie needs to be divided, felt like a backward step, a possible misuse of GP's time, and sometimes a gamble, for these women. One woman was asked who her GP was, as they were trying to keep track of which GPs were 'tongue tie friendly', or not. We have spoken to women whose GPs refused to refer for treatment, stating that division wouldn't help them to breastfeed.

We spoke to women who were told that there were no problems, because their babies were gaining weight. The clinicians were not taking into consideration the health of the mothers, who were experiencing pain and distress. In one case, a woman was told by her GP that she did not need a referral, because her baby was thriving on expressed milk. These women told us that baby's weight gain should not be the only measure of breastfeeding success.

Equal Access

Referrals for tongue tie division within the NHS in Cambridgeshire go either to the Maxillo Facial Unit at CUH or Plastic Surgery at NWAFT (formerly Hinchingbrooke), which may account for the long wait times. Whilst tongue tie division does not require special clinical setting or unusual equipment (private practitioners are insured to provide the procedure in people's homes), there is currently no provision for community based tongue tie division with adequate follow up support in Cambridgeshire.

According to staff at the Rosie, the tongue tie division service at CUH:

- Only takes referral for Anterior tongue ties. Other cases must be referred to Bedford.
- Currently (as of April 2017) has a 2-3 week wait.
- There is no support for feeding babies after the division takes place.

Without adequate breastfeeding support before, immediately after, and for the 2-4 weeks after a tongue tie division, there are still likely to be complications with breastfeeding that division alone cannot address.

Breastfeeding support workers often advise families to contact private lactation consultants who provide tongue tie division in the community. Most of the women we spoke to ultimately pursued private treatment through Sarah Oakley, lactation consultant and tongue tie division practitioner. The additional step of a GP appointment, the uncertainty of getting a referral, and the long wait times were all reasons given for pursuing private care, but private care is an expense that not all families can afford. Those who cannot afford it are left with a system that does not support them in their breastfeeding endeavours, despite extraordinary pressure put on new mothers to breastfeed.

Overall, these women told us about an inadequate, often inaccurate, and clearly unequal provision of service for tongue-tie that is interfering with mothers' and babies' abilities to breastfeed successfully. This, paired with extraordinary pressure to breastfeed is leaving mothers in physical pain and emotional distress. We would like to see tongue tie services reviewed, particularly to improve:

- Timely assessment of tongue tie, posterior and anterior, that may interfere with breastfeeding
- Clear, factual and transparent information provided to parents about what tongue tie is, how it can interfere with breastfeeding, and what services are available
- An uncomplicated referral pathway to tongue tie division when necessary, preferably removing unnecessary visits to the GP and accurate expectation setting regarding wait times.
- Equal access for women, regardless of income or geography, to a tongue tie division service that is community based, responsive, and incorporates the necessary support to help women and babies breastfeed successfully.

Models of Good Care

Lactation Consultants can offer services based in the community, perform tongue tie division from community based clinics or from people's homes, and provide breastfeeding support before, immediately after and follow up support as part of the tongue-tie care. This is a service that supports and enables women to breastfeed, when that is their goal. The private care available in Cambridgeshire offers an example of best practice from a care perspective, but is not equally available.

One model of commissioned, community based tongue tie services is Medway specialist breastfeeding clinic. This clinic is part of an infant feeding pathway and strategy- which is a collaborative effort that includes health visiting, maternity services, children's centres and voluntary organisations. Medway tongue-tie service is provided by Medway Community Healthcare, and is run from a children's centre. The referral process is via GP or Breastfeeding clinic. The clinical lead (infant feeding) is Wendy Brownrigg, registered nurse, lactation consultant, health visitor.

Local Support

There are a number of individuals in Cambridgeshire who are passionate about trying to improve the situation for women trying to breastfeed tongue tied babies. An informal network has developed, which includes many of those mentioned in this report, (including Sarah Oakley and Jo Watt), Rachel O'Leary (Chair of the Cambridge Breastfeeding Alliance), Lesley Bennett (Infant Feeding Lead Midwife at the Rosie) and other professionals seeking to support breastfeeding women. This network contacted Cambridgeshire and Peterborough CCG regarding tongue tie services in 2016. Communications between this network and the CCG were led by Rachel O'Leary and responded to by Dr. Richard Spiers.

The requests and concerns that this group put forward mirror those outlined in this report, in particular the need for high quality breastfeeding support before and after a timely tongue tie separation. The group also put forth specifications regarding levels of training and qualifications. This network has offered to advise and support any commissioners involved in tongue tie services.

In February of 2017, Dr. Spiers informed the group that the CCG had agreed to fund a region-wide, midwife led tongue tie service. We are excited by the prospect of a new service, but hope that it is developed fully utilising the wealth of local knowledge and experience available in the community.

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