British Association of Perinatal Medicine

Lactation and loss: Management of lactation following the death of a baby

A Framework for Practice

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Contents

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Who the Framework is for?

This framework is written for professionals working with parents and families to provide information and guidance in supporting mothers around lactation and loss, where a baby or child is not expected to survive, or has died. While the main focus of the document is around perinatal and neonatal death the group is mindful that mothers may be breastfeeding when they lose an older infant or child. In addition, we recognise that support is also necessary for partners and families around lactation after loss.

In this document, we use the term 'parent' to mean all parents, carers and legal guardians of a baby who has died, and the term 'mother' to mean all women and people who have given birth and initiated or established lactation for a baby who has died.

For professionals using this document and applying its guidance to practice, it is important to consider the individual circumstances and needs of each parent who may need this support. For social, cultural, or other reasons, parents may need specific information or support to enable them to make the choices they want, and which are most appropriate for them.

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Introduction

The death of a baby and subsequent grief is complex. In addition to grieving for their baby's life, parents grieve for the loss of the life they had imagined with their child, including their anticipated roles as parents. The emotional pain new mothers experience may be compounded by physical pain related to continued lactation when there is no longer a need to provide comfort and nutrition for their baby. Guidance on advising mothers regarding cessation of lactation following bereavement is not always readily available in the Delivery Suite, Neonatal Unit, Hospital or Hospice setting.

With multiple tasks to be completed alongside support for both the family and team members, this aspect may be overlooked, impacting heavily on maternal emotional and physical wellbeing. Providing education and guidance for teams on management of lactation after death of a baby is important and is underpinned by a knowledge of the physiology of lactation. The aim of this framework is to review lactation and loss and to utilise this knowledge to guide support for mothers and parents to make the choices which best suit their individual circumstances. This includes options around both cessation and continuation of lactation following the death of a baby.

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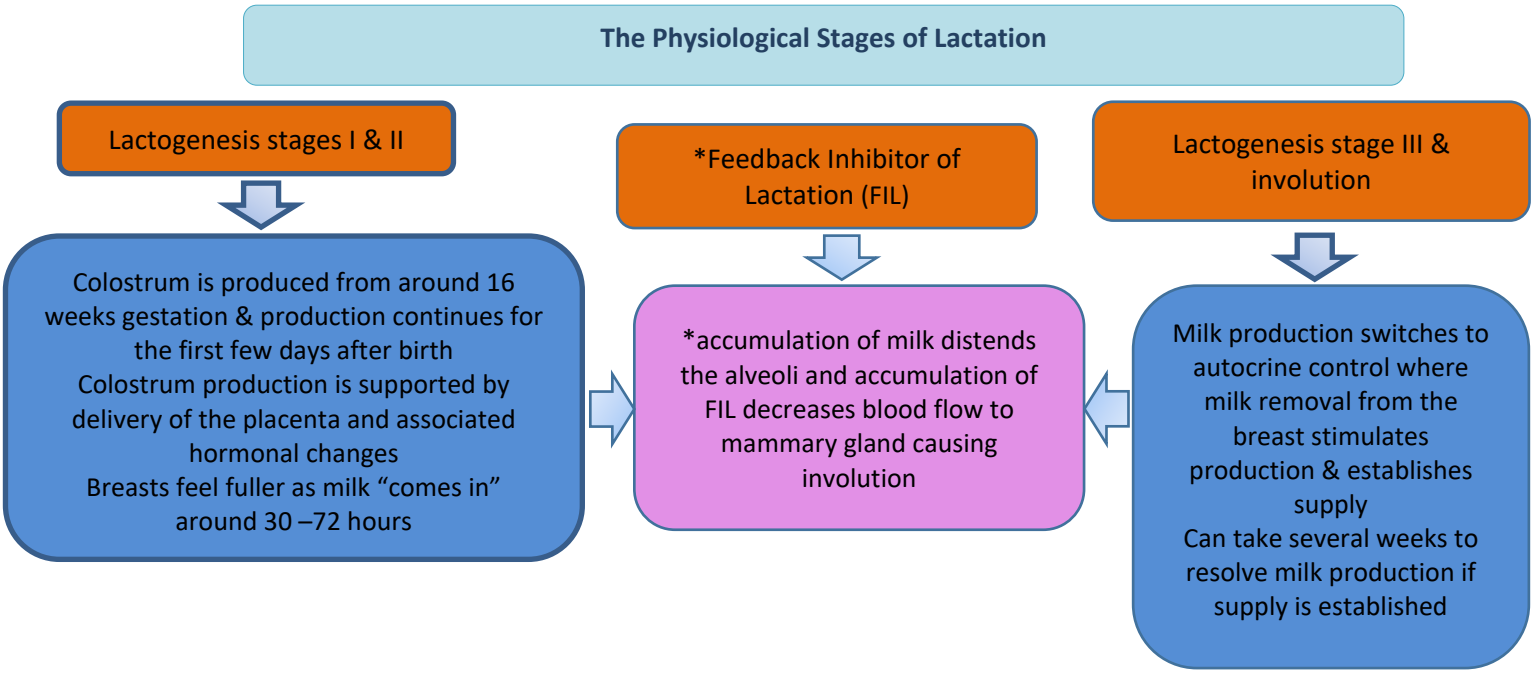
Lactation and grief: White tears

Grieving mothers often experience intense physical consequences after losing a baby. The milk produced by the mother after losing an infant has been referred to as 'white tears'[1], a descriptive term demonstrating the emotional weighting of this physiological phenomenon. The milk produced is inextricably linked with the mother's grief. Continuing Bonds Theory of grief proposes that grief is a fluid concept and that rather than the bereaved moving on from their grief, instead the memory of the deceased continues through their life and is incorporated into the ongoing narrative of their life[2]. The bereaved often look for ways to maintain bonds that have been broken by the bereavement. The ongoing production of milk can be a very real reminder of the loss they have experienced and for some mothers it may represent a continuing bond as they move along their bereavement journey.

Lactation Physiology



Knowledge of the physiology of lactation is important to support women to initiate and establish breastfeeding but as stated above is also advantageous in supporting bereaved mothers. Here we provide a brief overview as the stage of lactogenesis may be different depending on whether a baby is lost to stillbirth, dies shortly following delivery or after a mother has already established breastfeeding.

Mammary tissue is organised in lobes containing alveoli, blood vessels and lactiferous ducts. During pregnancy, the high progesterone:oestrogen ratio causes significant growth of breast tissue. From mid pregnancy the alveolar cells are capable of milk production. This is known as lactogenesis I (or secretory initiation). Milk secretion is inhibited (prevented) by high circulating levels of hormones (progesterone and oestrogen).

When the placenta is delivered, progesterone levels fall rapidly. This, along with raised levels of the hormone prolactin initiates lactogenesis II (or secretory activation), usually after 30-72 hours from

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birth[3]. This phase of lactation is hormonally driven and milk removal through breast milk expression or breastfeeding is not needed for this phase. Following lactogenesis II a switch occurs, with breastfeeding or expression now acting as the stimulus for milk production: this is called lactogenesis III and occurs from around 9 days post delivery and is maintained on a supply and demand mechanism.

When an infant suckles at the breast or the mother stimulates the breast to express milk, there is contraction of muscle cells and feedback to the brain to stimulate oxytocin release.

The detachment of the placenta from the wall of the uterus and subsequent reduction in circulating hormone levels allows prolactin hormone to initiate lactogenesis II and milk production occurs after 30-40 hours. If breasts are not stimulated to produce milk after birth, for example if the baby dies shortly after delivery or is stillborn and feeding or expression has not taken place, accumulation of milk in the breasts distends the ducts and leads to accumulation of 'feedback inhibitor of lactation' (FIL) in the breast. This causes a decrease in size of the milk secreting glands, thus reducing milk production[4]. This process can take a number of weeks to resolve and the resulting breast engorgement can be uncomfortable. Painful engorgement can occur and this should be avoided.

After delivery, if an infant has been breastfeeding or admitted to a neonatal unit and the mother has been expressing regularly, she may have established a milk supply. This is also relevant to babies admitted to hospital beyond the newborn period or who die outside hospital. Lactation suppression in this situation is different and more likely to be protracted. It is very important to recognise that for some mothers, lactation suppression is not their preferred journey and some will wish to continue to express for milk donation. Further detail on the physiology of lactation is provided in Appendix 1.

Knowledge of the stage of lactogenesis can help professionals to support mothers and families.

Timing of death and stage of Lactogenesis

	Stage of Lactogenesis
Stillbirth – a baby who has died before or during birth	Lactogenesis I
Early loss – defined here as a baby who dies within the first few days after birth	Lactogenesis II
Later Loss – defined here as a baby who dies after at least the first week. Can include older children.	Lactogenesis III
Multiple pregnancy with surviving baby OR older sibling being breastfed	Lactogenesis I - Lactogenesis III

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Managing Lactation and Loss

End of Life Care Considerations

For neonates and infants who are receiving end of life care maternal expressed milk can be used for mouth care and mothers can place some milk on their baby's lips[5]. As a symbolic act, this may bring comfort for the mother and help to connect the mother with her baby. Some dying babies may be able to suckle at the breast and again this option could be offered to the mother, if appropriate[6]. Further detail on end of life care will be available in the BAPM Palliative Care Framework for Practice in due course.

If there is an opportunity before the time of death it is important to explore with mothers and families their wishes regarding lactation. This is a busy time and it is essential that lactation is addressed. It may also be appropriate to explore a mother's wishes before end of life, with a palliative care approach and Advance Care Planning or as part of the birth plan. As stated above mothers may wish to cease breastfeeding and follow a lactation suppression pathway or may continue to express and donate breastmilk – *continuation of lactation*. Mothers could also be breastfeeding a sibling and need support in establishing or continuing lactation.

Cultural, spiritual and social considerations

It is important to consider the impact of lactation and loss in relation to cultural and spiritual belief systems. Healthcare has increasingly moved away from 'cultural competency' towards the reflective and inclusive discussion of 'cultural humility' which incorporates a lifelong commitment to self-evaluation and self-critique, to redressing the power imbalances in the patient-physician dynamic, and to developing mutually beneficial and nonpaternalistic clinical and advocacy partnerships with communities. Cultural humility involves encounters of different world views, including your own, but also with the person you are interacting with, whether a patient or a family member. It also involves recognising that we may often make assumptions based on others' cultures and backgrounds, and highlights the importance of being open to asking questions and to practice reflective listening, a process which recognises that others are the experts about their own lives.

Asking broad and non-directive questions about spiritual and religious beliefs has also been discussed by many who have worked in palliative care[7], remembering that religious beliefs are a subset of spiritual beliefs, both of which can give additional cultural frames, and religious leaders may be helpful around the time of death and dying.

Rather than offer a list of specific cultural considerations related to both lactation and loss, we suggest that you might want to consider a recent discussion from Australia[8] which reviews for the five major religions' (Islam, Buddhism, Hinduism, Christianity and Judaism) key considerations for clinicians providing palliative care for infants and their parents, but only highlights breastfeeding under the Islamic tradition. Religious frames for clinical considerations regarding breastfeeding may be important for other traditions. United Kingdom Association of Milk Banking (UKAMB https://ukamb.org) and others[9] have been involved in discussions regarding the complex Islamic tradition of milk kinship, and therefore might be able to offer additional guidance. Providing physiological information about bodily experiences regarding lactation after loss forms the beginning of this conversation. For further information on different cultural and faith groups see Appendix 2

Lactation and loss: Impact upon families

The healthcare team should serve to support fathers, partners and the wider family following perinatal loss and assist in helping them and the mother to create meaning through the sharing of

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the story loss, the facilitation of sociocultural rituals associated with loss, the provision of mementos as appropriate, sensitive presence, and the validation of the loss at individual and family level. Supporting the mother with her choice with regard to lactation following perinatal loss and creation of breastmilk mementos, if she so wishes, are important areas of support by the father or partner and the wider family.

LGBTQ

Many nursing parents are from LGBTQ+ families and have variable experiences of nursing their infants and encounters with health care professionals that can range from supportive to discriminative and exclusive. While it is always important to be inclusive as health care professionals, this is even more important for bereaved parents. It is beyond the scope of this document to cover the complexities of the LGBTQ+ experience but appropriate terminology is vital and the best way to support families involves finding out and using their preferred pronouns and ensure language includes non-gendered terms[10, 11].

Many non-gestational parents choose to nurse their baby and do so for a variety of reasons such as attachment, nutrition and sharing the caregiving role[12]. These parents have travelled along different paths to nurse their child and this may not be known to the team supporting the family at the time of bereavement. Sometimes lactation will have commenced prior to birth/adoption in preparation for parenting. It is important to include non-gestational lactating parents and treat them equally to gestational parents and acknowledge their unique journey.

Non-gestational parents refers to adoptive parents, intended parents (through surrogacy, parents whose partners are birthing and transwomen). If both parents nurse their baby it is called co-nursing

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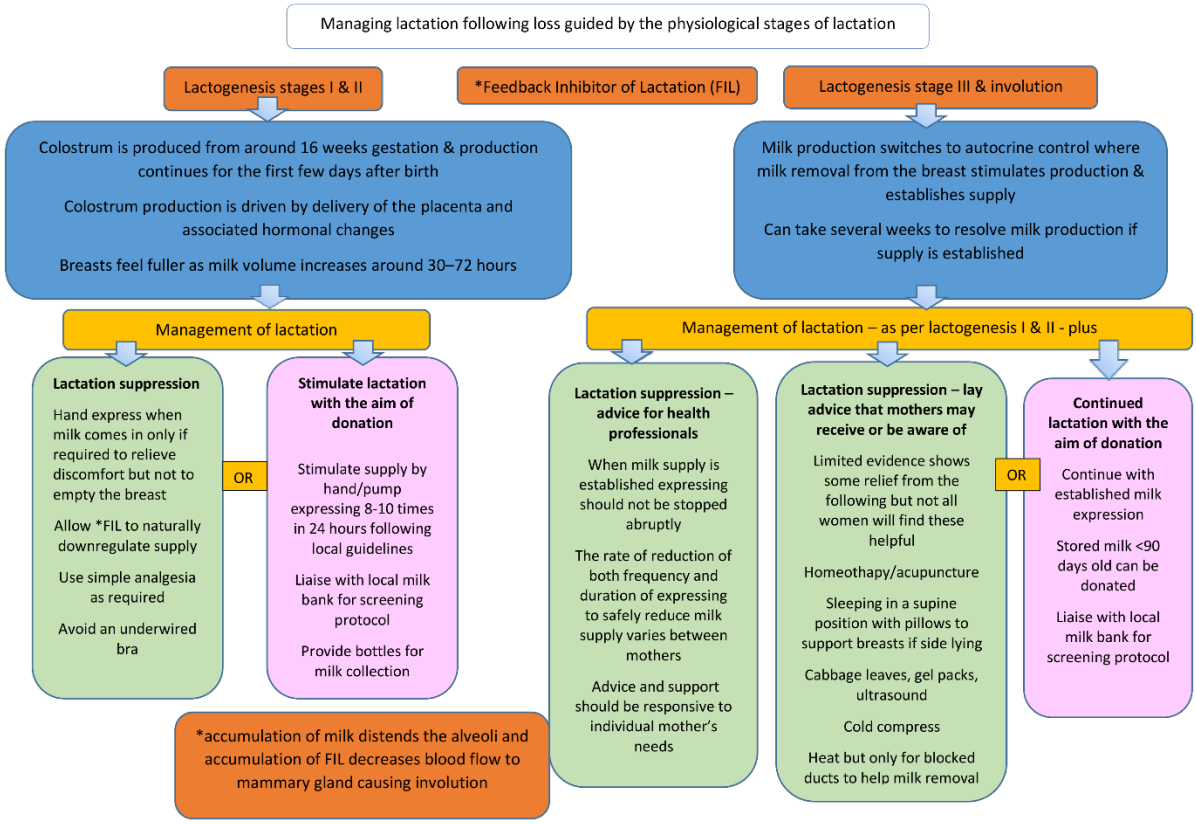
Managing lactation after loss

Managing lactation after loss is dependant upon the route that mothers and families choose to take and is guided by the stage of lactogenesis. Details on the different approaches are discussed below. Lactation suppression is a choice that some mothers make, while others may wish to initiate or continue lactation as part of the narrative around their baby's death. Whatever they choose to do should be discussed openly and supported as appropriate. The chart below helps support professionals in planning management of lactation after loss.



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Lactation suppression

Lactation suppression can be managed by pharmacological and non-pharmacological methods.

Lactation suppression: non-pharmacological methods

Historically, many methods of suppressing milk have been recommended, the majority of which make little difference. In the past, many non-pharmacological approaches to lactation suppression have been recommended that have no beneficial effect, including breast binding[2], the use of ice, fluid restriction and forced fluids[13]. It's important for professionals to be aware of different practices as mothers and partners may bring up some of these practices.

Lay advice

- There is some weak evidence that homeopathy[6] and acupuncture[14] may have a beneficial effect, however there is not sufficient evidence to justify recommendation[15].
- A well supporting bra should be worn day and night[16].
- Use of breast pads within the bra can help with breast leakage.
- Sleeping in a supine position (on your back) may take pressure off the breasts to aid a more restful sleep; pillows can be used to support the breasts if side lying.
- Some 'traditional' treatments may help, such as cabbage leaves, although this may be due to the gentle massage that is involved rather than the treatment per se[17, 18]. There is some evidence that phytoestrogens in the cabbage leaves may reduce swelling in the tissues. Similarly gel packs and therapeutic ultrasound (not available in the UK) have shown benefit by the same presumed mechanism[5, 17].
- A cold compress may help – apply for 15-20 minutes[16].
- Heat should usually be avoided[16] – advise mother to shower with her back to the water[18], though some people report finding heat to induce some leaking beneficial to their comfort
- Simple analgesia may help with the discomfort[16], such as paracetamol or a non-steroidal anti-inflammatory unless there are contraindications to these medications; .

It is worth noting, that although the evidence shows breast binding is not an effective intervention, one study found mothers reported the process of undergoing breast binding as positive as it gives rise to conversation about their grief and a physical reminder of the loss as being real[19]. Breast binding is also the cultural norm in some areas[15]. If mothers choose this option it is important to be aware that there is an increased risk of mastitis and they should be vigilant to this[15].

As breast engorgement and subsequent negative feedback mechanisms work to suppress lactation, it is important to explain this to mothers. The aim when suppressing lactation is to avoid painful engorgement. For mothers with an established milk supply, abrupt withdrawal is not advised as it can lead to severe engorgement and intense pain[13]. There are different reported methods of pumping designed to reduce the production of breastmilk. The frequency and duration of pumping will vary from one woman to another, depending upon multiple factors such as how much milk she produces[13]. Mothers should continue to express using a good quality breast pump, unless she is experienced in manual expression[20], thus one should be supplied. Removing just enough milk to reduce the discomfort, but not emptying the breast will gradually reduce lactation[13, 16].

Discussing the principles and physiology of reducing lactation and formulating an individualised plan for expressing with the mother is likely to improve understanding as well as giving her some control of the situation at a time when she is likely to feel she has no control[18]. If the mother has an established schedule for expressing, she may prefer to have a schedule to follow to reduce her supply. Some examples include to drop one session per day and therefore alter the interval between

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them accordingly[16, 18], or to reduce the time of each expression by five minutes. Example of a plan shown in Appendix 3.

When undertaking steps to gradually wean breastmilk supply, engorgement and milk trapping can occur. Plugged ducts or trapping might be described as a tender spot or lump in the breast. Suitable advice to give the mother experiencing this would include massaging before, during and after pumping to assist with removal and stroke towards the nipple to encourage this milk to flow[21]. Heat applied prior to expressing may aid this[16]. Mothers should be advised that if it worsens by becoming larger, hardening and involving the entire breast, then this is engorgement and unaddressed this can lead to mastitis. Mastitis presents as sore, engorged breasts that are erythematous and warm to touch. Remain mindful of the different ways inflammation can be observed depending on skin tone. Flu-like symptoms such as fever, chills and myalgia may be present[16]. These women should be referred to their own clinician for treatment. It is important to inform mothers that leaking milk may be experienced for weeks to months after lactation is suppressed[16].

Suggested advice that could be given to mothers is included in Figure 2 below. The authors are mindful as stated above that practices around lactation and loss vary according to culture and belief systems. It is important for professionals to recognise and acknowledge different practices when engaging with mothers and families whilst exploring options for managing lactation after the death of a child.

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Figure 2: Suggested advice for bereaved mothers who are undertaking lactation suppression.

Advice for bereaved lactating parents

- Wear a well supporting bra day and night – for example a sports bra
- Breast pads in your bra will help with leaking
- Sleep on your back, pillows may help to support your breasts if you sleep on your side
- Gentle massage may help; some traditional methods such as cabbage leaves in your bra or using gel packs may help by providing gentle massage.
- A cold compress may help – apply for 15-20 minutes
- Heat should be avoided as this can lead to leakage (although this may be helpful with painful engorgement and plugging); when showering heat can be avoided by standing with your back to the water
- Simple analgesia can help with the discomfort if you are usually able to take these medications – paracetamol 1g four times a day and an anti-inflammatory such as ibuprofen 400mg three times a day. These can be taken together.
- Some women like treatments such as acupuncture and homeopathy. There is no evidence of harm with these treatments
- Gradual weaning of expressing is preferred to abruptly stopping due to the increased risk of mastitis and painful engorgement. Together with your babies care team you can decide on a way to do this:
    - Expressing when you are very uncomfortable and ensuring you don't empty the breasts
    - Reducing the period of time you express for – for example if you express for 25 minutes each session, reduce this by 5 minutes every day
    - Reducing the number of times you express each day – for example if you express 8 times a day/three hourly – reduce this by one session a day – e.g. to 7 times a day or every three and a half hours

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Lactation Suppression: Pharmacological methods

Historically, many medications have been purported to induce or aid lactation suppression, including oestrogen, testosterone and bromocriptine[15] which are no longer used due to their cardiovascular side effects[22-24]. Cabergoline, a dopamine agonist used for hyperprolactinaemia, has previously been shown to successfully suppress lactation in a high proportion of women (>90%) and is well tolerated by the majority of them[25]. Dopamine agonists are recommended by the Royal College of Obstetrics and Gynaecology for lactation suppression in women who experience a stillbirth[26] https://www.rcog.org.uk/media/0fefdrk4/gtg_55.pdf). Cabergoline is simpler to use and has less adverse effects than bromocriptine[25].

Cabergoline has two treatment regimes, depending upon whether one is in the first 24 hours after delivery or after this time[27]. The dosing regime and other pharmacological information are outlined in Figure 3 below. Commonly reported side effects of cabergoline are dizziness, headache and nausea. Counselling should cover these together with the rarer side effects as documented in the latest version of the British National Formulary[27].

Each maternity and neonatal service should look locally at how best to facilitate the process of prescription and supply, which may be through maternity services or the GP. Medication for the lactating parent should be prescribed by a clinician caring for the parent rather than the baby. Having clear guidance is important to pre-empt confusion for mothers, families or staff following a baby's death. Each Trust, Health Board, Health Care organisation providing care to lactating mothers, babies and children should have an agreed pathway for the use and prescription of the medication. For death outside maternity care and neonatal departments, local arrangements should be in place to provide support and arrange prescriptions as necessary.

Figure 3: Cabergoline prescription regime, contraindications and side effects[27]

This medication is not without potential side effects and mothers must be counselled accordingly prior to its prescription.

Prevention of lactation

- 1mg to be taken as a single dose on the first day post partum

Suppression of established lactation

- 250 micrograms every 12 hours for 2 days

For up to date information please see the most recent version of the British National Formulary

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Parent stories

> I was given a leaflet which explained options including expressing and donating. Unfortunately I only got the leaflet after I'd been given cabergoline. Realistically I don't think I could have carried on expressing for a long time but I was sad that the choice had been removed from me.

> We were offered meds almost as soon as Elliot was born. I had already decided I wanted to donate my milk. The Midwives didn't have a clue what I was talking about when I ask them how to go about doing so and despite saying they would find out for me, no one ever did. I ended up doing some Google research and got in contact with the north west milk bank. It felt like a really positive think to do in Elliot's memory and gave me something to focus on doing in the weeks at home afterwards. I gave up after 6 weeks, not just because we knew we wanted to TTC [try to conceive] again but supply had dropped massively. What I wasn't prepared for was the feeling of loss again when they came to collect the frozen store of milk. Absolutely gut wrenching and I think it hit me hard because I wasn't expecting it.

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> I expressed for five days whilst Arlo was on NICU. My milk had come in just as he died. I asked to have something to suppress my supply as it was a cruel torture after he died. I remember sobbing in the shower as my boobs leaked. I wasn't offered anything/ it was never discussed, but I asked the midwife who had to ask O&G who weren't very helpful. I was wary of taking anything that would effect my periods returning which they suggested might happen. Still have no idea what the truth is?!
>
> I think it would be great if more knowledge was available to bereaved mums so that they can decide whether to have it or not before getting engorged/painful breasts or crying over leaking breasts and feeling like they have no control over a situation which could have been minimised with better and earlier communication.

> I was offered cabergoline to suppress lactation (this was thoughtfully discussed antenatally by my wonderful obstetrician as well as immediately after Teddy was born, as he wasn't expected to survive). I took up the offer and it worked well for me.
>
> I seriously considered milk donation, having heard about other mums doing this in similar situations, but decided against it because I wanted to try to conceive again soon. I would have welcomed the obstetric team bringing up this option, if I hadn't already come across it. I appreciate that this would need to be tactfully done though, as its not something that everyone would find helpful.

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Staff stories

One night a baby with significant cardiac disease died after many months on our unit. I was talking with the Mother and she had painful engorgement. She did not wish to continue expressing apart from relief and it was really challenging to find someone to prescribe cabergoline for her. Eventually, a member of the Obstetric team came up to the NICU to prescribe it. This all took time to arrange and a guideline would have been helpful.

Neonatal Consultant

When I was working in the paediatric emergency department I cared for a family whose baby had died suddenly in the night at a few months old. The mother was in a lot of pain from engorgement as the baby usually breastfed several times in the night and this wasn't on anyone's radar to plan for and help with. I will always remember her description of the police watching her express milk at home, having just finished attempting to resuscitate her baby. I am much more aware of the need to discuss acute expressing at the time of the sudden death of a breastfeeding baby and making a plan for suppression or continuation of lactation before the family leave the acute setting.

Neonatal Registrar

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I had the privilege to meet a mother antenatally following her baby's diagnosis of Anencephaly. Over a period of a several months, we met to develop a Birth Plan and Advance Care Plan, focusing on what was important for her and her baby. It was important to her to enjoy her pregnancy as much as possible and to experience being a mother for whatever time she had with her baby. We discussed lactation and possibilities for expressing her milk and donation of breastmilk. She decided that she would like to try to feed her baby if at all possible, give her drops of expressed breast milk, and then continue expressing for the purposes of donation, which would be in memory of her baby. From my perspective, it felt really positive to be able to have the time to truly understand what was important for this Mum, and how I could help and support her to ensure it was a reality. We couldn't change the outcome for her baby, but together we planned how to maximise and enhance their experience together as a family.
Fetal Medicine Specialist Midwife

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Lactation continuation

Milk donation

Some mothers will express less as part of their gradual suppression of lactation. Other mothers may choose to continue to express milk in the longer term after their baby has died. The sharing of maternal milk is steeped in history with cross feeding and wet nursing[28]. The first formal milk bank was opened in Vienna in 1909[29] and now there are over 600 milk banks operating over 60 countries[30], non-profit organisations that collect, pasteurise and distribute donated expressed breast milk to those who need it. Milk is donated for many reasons, one of which will be bereavement.

Many others are comforted by the knowledge that the milk they have produced can help a baby in need[31], taking comfort in the 'legacy' left by their child[28]. Welborn explored the experience of 21 bereaved mothers who chose to continue to express and donate their breastmilk[32]. The data revealed four themes; the first of which was that it allowed the mothers to identify themselves as a mother, a way to feel like a mother in the absence of their baby. Expressing milk gave mothers a sense of meaning associated with the act, a physical connection with their baby and a way of acknowledging their baby's life. The third theme centred around finding meaning in the perinatal loss: the act of donating milk for other infants gave mothers a deeper meaning beyond the intense grief, allowing other infants to benefit in honour of their babies, bringing comfort to the mothers. The fourth theme centred upon the support that they received regarding lactation after their bereavement, many feeling that they did not receive enough support and that the option to donate milk should be more accessible. All 21 mothers interviewed in this study reported positive emotions regarding their experience of donating milk, thus it is an option that should be sensitively offered and compassionately supported if this option feels right to the mother.

If a mother has expressed prior to death, after death or as part of lactation suppression, they may have a supply of frozen or refrigerated expressed breast milk. Milk can be donated formally though milk banks and the United Kingdom has 15 milk banks. Information regarding these can be found via the UKAMB, a charitable organisation that supports milk donation and NHS-recognised milk banks across the UK[33] (http://www.ukamb.org/). UKAMB supports the Memory Milk Gift Initiative. It would be best practice to contact the milk bank prior to discussing this option with mothers as there are eligibility criteria and at times banks are unable to accept donations. Having this knowledge prior to discussions can avoid upsetting mothers further by suggesting it as an option and then giving them a sense of failure or disappointment if they are unable to donate[18, 31]. Donation to a milk bank is the safest way to donate milk. Milk may be used for various reasons. See Appendix 4.

Lactating parents should be made aware that in certain circumstances milk may not be able to be donated for clinical use. See appendix 5 for contra indications to clinical donation and refer to www.ukamb.org/medication-and-donating-breastmilk-2/ for the most up to date medication information. In these circumstances families will be offered the opportunity to donate milk to a milk bank for research purposes. This research may be a specific research project or used to help ensure best practice in UK milk banking. Examples of how milk could be used include temperature trials and milk composition analysis. This research will ***never*** involve formula milk companies. When making a donation for research, blood samples are not required. For women who have some milk stored but are unable to donate the milk, they can be advised to discard the milk through general waste collection. Some women may wish to keep a container of milk as a memento[16]. Women can also be advised that there are also companies that turn breast milk into mementoes such as beads or pendants for a fee. For examples of memorabilia, see Appendix 5.

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Best practice for milk donation after loss

- Contact local milk bank- details can be found here www.ukamb.org/find-a-milk-bank or Memory Milk Gift (memory.milkgift@nhs.net) to confirm which milk bank is able to accept donation and whether relevant memory making opportunities are available. Refer to Appendix 4 for initial guidance and contact details.
- When discussing lactation suppressant always offer the option of milk donation.
- Take the time to discuss the potential benefits of donation to the donor and recipients.
- Have literature available for family to take away.
- Pre-screen the family to determine whether the milk will be used for donation or research.
- Gain a signed consent form.
- If milk is for donation – refer to milk bank as to whether to take blood samples on site or refer to community facilities.
- If taking samples on site arrange for delivery to milk bank e.g. via blood bikers or postal service.
- Pass referral to Milk Bank via telephone or via email – see Appendix 4.

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Parent stories

I donated milk after my son passed away at 41 weeks. He was still born. No one mentioned that I could donate my milk - something that my body was going to start producing because even though he had passed away he was still going to be born and my body thought he needed to be fed. Whilst I was waiting for the induction medication to work, which takes 48 hours, I started to research babyloss, about what my body was going to go through and I stumbled across the fact that I could donate my milk, Bodhi's milk. Straight away I knew it was something I wanted to do, in his name. I wanted something that I made for him, to go to other babies, to help other families. Some of my family members and even the consultants had concerns for my mental health when I told them I wanted to donate. But actually it was the best thing for my mental health. It gave me a reason to look after myself in a really dark time when otherwise I'm not sure what I would have done.

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Staff stories

I cared for Baby Tom over a period of 3 months on a neonatal unit, he had a twin brother called Baby Sam who died shortly after birth. The twin boys were born extremely prematurely and Tom was ventilated for a total of 94 days. He suddenly deteriorated and subsequently died. When Sam died, the boy's mother, Alice felt she didn't have an opportunity to grieve properly for him, as she focused all her attention on Tom. She continued expressing milk, but Tom was never able to be feed with her milk. When Tom died I was able to discuss with Alice, the options which were available for her stored frozen milk and provide guidance on lactation. I supported her to make the right decision for her, which was to donate her stored frozen milk in memory of both Sam and Tom, and her wish was to suppress lactation. It felt so positive to be able to share the information with her regarding her stored frozen milk, and that it could be done in memory of both her boys.
Senior Neonatal Nurse

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FOREVER

As stated above it is important to explore options with mothers and families whilst being mindful of cultural, spiritual beliefs and social circumstances. This document provides a framework for exploring these options around lactation and loss – the **FOREVER** acronym. Further information on suggestions for starting conversations is available in Appendix 7.

Before going through the **FOREVER** acronym, be aware of arrangements at your local Milk Bank for donation following bereavement including ways to donate, guidelines for donation and contraindications for donation: see Appendix 6.

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F	Families	Recognise the importance of input from families and their support for mother in decisions around lactation
O	Open Discussion	Have open discussion and explore Mother's feeling about plans for management of lactation eg continuation or cessation. This will be affected by many variables.
R	Revisit	Be prepared to review and have ongoing conversations on feelings and thoughts
E	Explore and Explain	Explain the different options available within service If plans for cessation discuss reduction in pumping times and both non pharmacological and pharmacological methods for cessation reduction If plans for continuation discuss options for local Milk Bank donation
V	Validate	Help and support the Mother and family to feel heard and understood. Recognise and acknowledge their feelings
E	Empathise	Feel with the Mother and families and remain non judgemental
R	Respect and Review	Respect the decision that Mothers and partners make with an appreciation of how their values and beliefs affect those decisions

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RESEARCH – Lactation and Loss

Whilst there is strong parent and healthcare support for the Lactation after Loss initiative, further research is required to evaluate the positive impacts along with better identification of barriers and facilitators that may enable more widespread adoption. Future research should consider multiple aspects including:

- Robustly documenting and evaluating the impact on maternal mental health within the context of trauma informed care.
- Determining any un-met needs and defining the key components of care to best support donating mothers.
- Identification of educational needs and co-designing training packages for healthcare staff
- Determining the views and experiences of healthcare professionals that may help or hinder more widespread adoption.

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APPENDICES

Appendix 1: Physiology of Lactation

Mammary glands are organised in lobes containing alveoli, blood vessels and lactiferous ducts. During pregnancy, the high progesterone:oestrogen ratio causes significant hypertrophy of the breast tissue (mammogenesis). From mid gestation the alveolar cells are capable of milk production. This is lactogenesis I or secretory initiation. Milk secretion is inhibited by high circulating levels of progesterone and oestrogen.

When the placenta is delivered, serum progesterone levels fall rapidly. This abrupt withdrawal of progesterone in the presence of raised circulating prolactin initiates lactogenesis II, or secretory activation, usually 30-40 hours after birth[3]. This phase of lactation is hormonally driven and milk removal is not needed for initiation of lactogenesis II. After lactogenesis II there is a switch from endocrine control to autocrine control, with milk removal acting as the stimulus for milk synthesis. This is lactogenesis III.

When an infant suckles at the breast, there is contraction of myoepithelial cells and feedback to the hypothalamus via the afferent pathway to stimulate oxytocin release from the posterior pituitary gland.

As outlined above, the detachment of the placenta and subsequent reduction in circulating progesterone and oestrogen levels allows prolactin to initiate lactogenesis II and milk production occurs after 30-40 hours. If breasts are not stimulated to produce milk after birth, for example if the baby dies shortly after delivery or is stillborn and feeding or expression has not taken place, accumulation of milk in the breasts distends the alveoli and leads to accumulation of 'feedback inhibitor of lactation' (FIL) in the mammary gland. This reduces capillary blood flow and causes involution of the milk secreting glands, downregulating milk production through a negative feedback loop[4]. This process can take a number of weeks to resolve and the engorgement can be uncomfortable. Sometimes painful engorgement can occur and this should be avoided.

After delivery, if an infant has been breastfeeding or admitted to a neonatal unit and the mother has been expressing regularly, she may have established a milk supply. Lactation suppression in this situation is different and more likely to be protracted. It is very important to recognise that for some mothers, lactation suppression is not their preferred journey and some will wish to continue to express.

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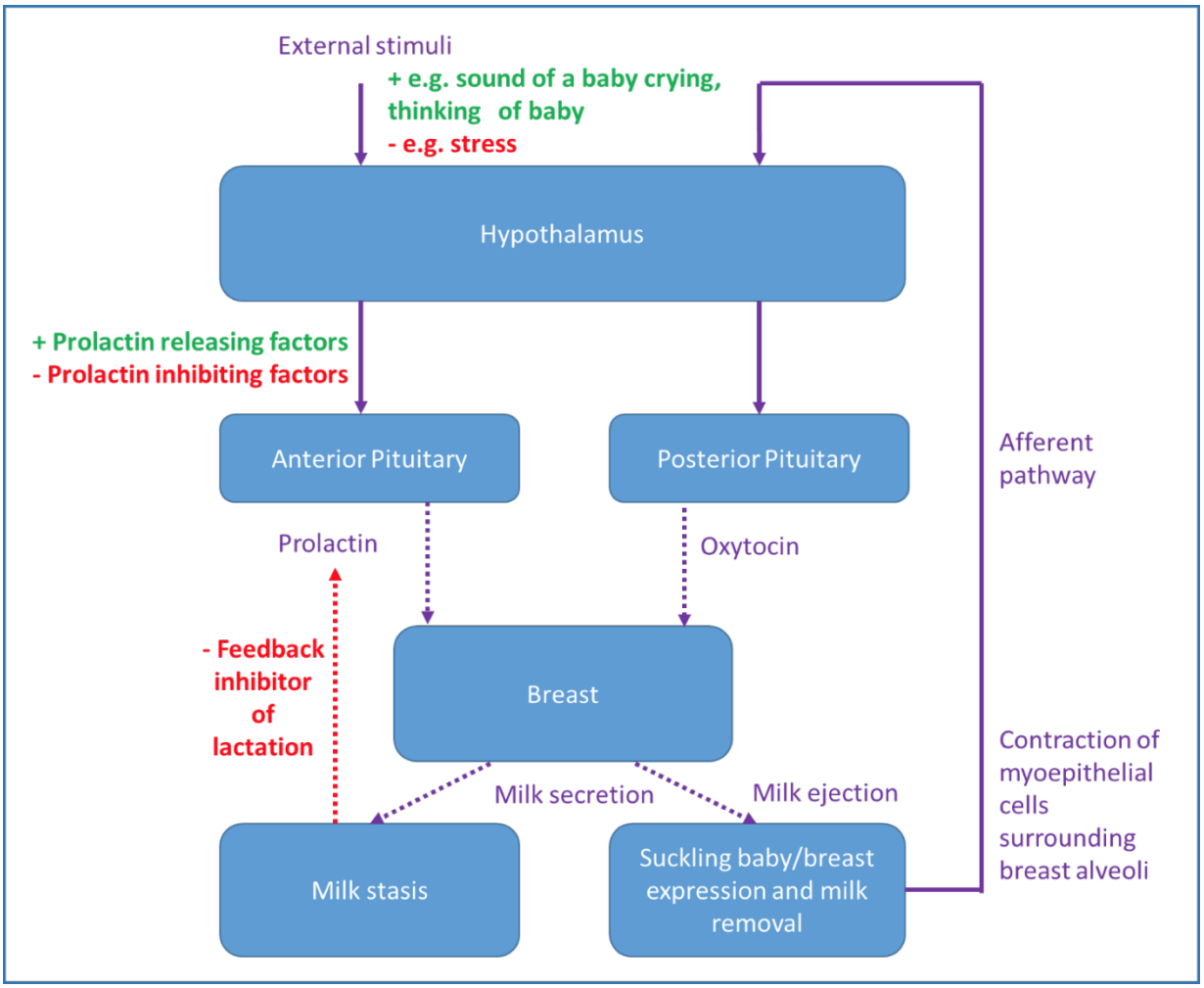
Physiology of Lactation



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Appendix 2: Organisations providing support

Child Bereavement UK: https://www.childbereavementuk.org

Children of Jannah: https://www.childrenofjannah.com

Jewish Bereavement Counselling Service: https://jbcs.org.uk

Legacy of Leo (LGBT resources and experiences): https://thelegacyofleo.com/lgbt-baby-loss/

Muslim bereavement support service: https://mbss.org.uk

National Bereavement Care Pathway (NBCP) Neonatal Death Bereavement Care Pathway: https://nbcpathway.org.uk

National Breastfeeding Helpline: https://www.nationalbreastfeedinghelpline.org.uk/

PATH (2019) A counselling guide for engaging bereaved mothers: A resource Toolkit for Establishing & Integrating Human Milk Bank Programs: https://www.path.org

Sands: https://www.sands.org.uk

The Neonatal Butterfly Project: https://www.neonatalbutterflyproject.org

Vishaal Foundation: https://vishaalfoundation.org

Willow's Rainbox: https://willowsrainbowbox.co.uk/south-asian-communities/

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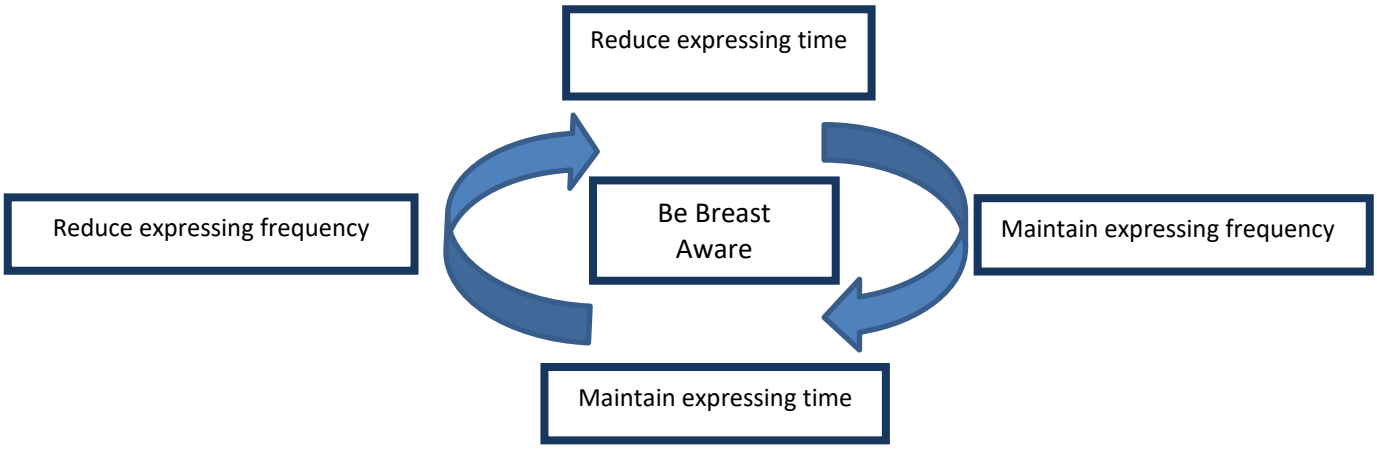
Appendix 3: Example of plan for lactation cessation

Considerations prior to planning a reduction in expressing.

1. Determine the duration of frequency and duration of breastfeeding and/or expression within a 24 hour period and base expression reduction on individual need.
2. Determine whether using an electric or manual pump, or whether hand expressing.
3. Advise lactating parent to be breast aware – to monitor any areas of redness or soreness and to be aware of general health. Seek medical advice if a fever develops.

Example of a plan for a lactating parent who is expressing 6 times a day for 20 mins per session.



Example Pumping Plan to reduce expression

DAY	EXPRESSING TIME (mins)	EXPRESSING FREQUENCY (per 24 hours)	Examples of timings
1-2	Reduce to 17	Maintain at 6	00:00, 04:00, 08:00, 12:00, 16:00. 20:00
2-4	Maintain at 17	Reduce to 5	00:00, 5:00, 10:00, 14:00, 19:00 23:00
4-6	Reduce to 14	Maintain at 5	03:30, 08:30, 13:30, 18:30, 23:30
6-8	Maintain at 14	Reduce to 4	05:30, 11:30, 16:30, 22:30
8-10	Reduce to 10	Maintain at 4	05:00, 11:00, 17:00, 23:00
10-12	Maintain at 10	Reduce to 3	06:00, 13:00, 20:00
12-14	Reduce to 6	Maintain at 3	05:00, 12:00, 19:00
14-16	Maintain at 6	Reduce to 2	07:00 19:00
Onwards	EXPRESS FOR COMFORT ONLY	EXPRESS FOR COMFORT ONLY	EXPRESS FOR COMFORT ONLY

- Note times are for example only.
- If using an electric pump reduce suction on each reduction of expressing length.
- Important to advise lactating parent of times when it may be important to express e.g. prior to funeral to reduce engorgement or leaking.
- Each plan should be individualised to the parent.
- Important the lactating parent understands that the process can go at own speed, if breasts are not sore then it may be possible to reduce length of expression or frequency of expressing at a faster rate. Also important to understand the importance of expressing if evidence of blocked duct.

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Appendix 4: UK Milk Banks and Donation Opportunities:

Milk Bank	**Email Address**	**Accepts Milk From Bereaved Donors for Donation**	**Accepts Milk from Bereaved Donors for Research/ Quality Control** (when due to medication/lifestyle donor milk is not compatible with donation to a neonatal unit)	**Memory Making Opportunities**	**Member of Memory Milk Gift Initiative**
Birmingham Women's and Children's NHS	bwc.milkbank@nhs.net	Yes	No	Memory Pebble. Memory Milk Tree print and option to have name on tree. Certificate. Dedication Square	Yes
Calderdale and Huddersfield NHS	For most up to date contact contact: info@ukamb.org	Yes	No	Memory Pebble. Memory Milk Tree print and option to have name on tree. Certificate. Dedication Square	Yes
Guys and St Thomas' NHS	milkbank@gstt.nhs.uk	---	---	---	---
Hearts Milk Bank	info@heartsmilkbank.org	Yes	Yes	Yes – a candle	No
Western Trust Milk Bank	tmb.irvinestown@westerntrust.hscni.net	Yes	If research project available	Yes – a badge	No
Kings College Hospital NHS	Not currently operational	N/A	N/A	N/A	N/A
The Milk Bank at Chester NHS	milkbank.chester@nhs.net	Yes	Yes	Memory Pebble. Memory Milk Tree print and option to have name on tree. Certificate. Dedication Square	Yes
Milk Bank Scotland NHS Scotland	donor.milkbank@ggc.scot.nhs.uk	Yes	Yes	Memory Pebble. Memory Milk Tree print	Yes

				and option to have name on tree. Certificate. Dedication Square	
Addenbrookes NHS	For most up to date contact contact: info@ukamb.org	Yes	No	No	No
Oxford Human Milk Bank NHS	For most up to date contact contact: info@ukamb.org	Yes	No	Memory Pebble. Memory Milk Tree print and option to have name on tree. Certificate. Dedication Square	Yes
Queen Charlotte's and Chelsea Hospital NHS	Imperial.milkbank@nhs.net	---	---	---	---
Southampton Human Milk Bank NHS	milkbank@uhs.nhs.uk	Yes	No	Memory Pebble. Memory Milk Tree print and option to have name on tree. Certificate. Dedication Square	Yes
The Southwest Neonatal Network Milk Bank NHS	Milk.bank@nbt.nhs.uk	Yes	If research project available. Wouldn't accept for in house research	Yes – a token	No
St George's Hospital Milk Bank NHS	milk.bank@nhs.net	Yes	Yes	Memory Pebble. Memory Milk Tree print and option to have name on tree. Certificate. Dedication Square	Yes
St Peter's Hospital Milk Bank NHS	asp-tr.sph.milkbank@nhs.net	---	---	---	---

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Appendix 5: Examples of breastmilk memorabilia

Appendix 6: Contraindications to Donation

- Medications – these may be short term contraindications dependant on medication type. Commonly include but not restricted to; anti-depressants, antibiotics, anti-coagulants, pain relief and induction medication following a still birth.
- Smoker in the household
- Donor uses nicotine replacement therapies or smokes.
- Alcohol consumption in excess of 1-2 units of alcohol once or twice a week.
- Caffeine intake of more than 200mg per day
- Milk expressed more than 10 weeks previously.
- Blood transfusion/tattoos/acupuncture may contra-indicate a retrospective donation due to delayed blood tests.

Appendix 7: Suggestions for how to start conversations

As healthcare professionals, it may feel difficult to approach a bereaved mother, to share information about lactation and milk supply at this most difficult and devastating time. However, it should form part of a conversation you may have about her physical health, and inform her about the natural changes in her body.

Here you will find some gentle suggestions about how to start a conversation. It is vitally important that you have these conversations and sharing of information as soon as you can, without avoidance. You can do this with acknowledgement, kindness and respect.

Discussing the choices surrounding lactation, lactation suppression and the possibility of donating milk after the death of a baby, may feel challenging to healthcare professionals. Staff should sensitively share information with women about donating their milk alongside doing nothing or lactation suppression (Neonatal Death Bereavement Care Pathway 2020)

This discussion may form part of a Palliative and End of Life Care plan which may also include a checklist. However, it may also be appropriate to have this discussion antenatally when a baby is not expected to survive, forming part of a Birth Plan or Advance Care Plan. [34, 35]

It's really important to create a space where we listen, truly listen to what's important for a mother and her family at that particular point in time.

Sometimes when we can be quite focused on our own agenda of asking questions and gathering information. It's important that mothers and their families are not rushed, and given the time they need with practical and emotional support.

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…….I understand that this is a really devastating time for you . There will be some natural changes associated with lactation and milk production. I would like to help you think about what suits you best……	
Immediately or shortly after birth	
I am so sorry your baby (name) died (if you don't already know the name of the baby, ask, and then ask mother's permission to use it). What's his/her name? Is it ok for me to say their name? *It is a natural and a normal process for your body to continue to make milk after the death of your baby* *There are some important details about lactation, your milk supply which I'd like to discuss with you. You have some choices to consider about your milk production…….* *Would this be a good time to go through them with you, or would you prefer for me to come back later this afternoon?* *If the mother says, now would be a good time……* *1.You can do nothing and let your milk reduce naturally (further information pg.11)* *2.You can take medication to stop lactation (milk production) (further information pg.11)* *3. You can consider continuing expressing and donating your breastmilk* *I can explain these options further to you when you feel it's the right time for you…….*	
……..There are several physical & emotional changes associated with milk production after giving birth. Your body is going to produce milk . Sometimes 2-5 days after delivery milk production continues. It's likely your breasts will become firm with the possibility of milk leaking and you may find your breasts may become engorged…..	
……..How can I support you right now? What would be helpful?.....	
When a baby has been on a Neonatal Unit	
……This is going to be a difficult conversation, but one which we need to have. I know you've been working so hard to build up and maintain your milk supply, and we need to think a little bit about your wishes on how you manage your milk supply now. *We don't need to have this conversation immediately now , but let me know when it suits you better….. Are you aware of the different options available to you? …..if not, we can explore these when you feel ready……* *….I know you were breastfeeding your baby, are you in any discomfort at the moment? Your body will continue to produce milk and we need to make sure that you don't become uncomfortable with engorged breasts which can be quite painful……Would you like to talk about this now, or would you prefer me to come back in a little while?.....*	
If there is stored breast milk in the freezer or at home	
…….When is the best time to discuss this?..... Usually at the same time you have the conversation about the expected physiological changes & lactation *……Have you thought about what you might like to do with your stored milk? There are several options, would you like me to go through these with you now? If you prefer we can have this conversation later at a time which suits you.* *There are some different options…….you could choose to take it home with you, you might like to*	

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discuss the possibility of donating your milk, or you may consider the staff taking care of it sensitively on your behalf. I can talk through the details of each of these, but there is no urgency to do that at the moment…….. *There's no rush and whilst you're deciding, we will continue to look after your milk for you.* *Some mothers who have an older baby, toddler or child decide to take their milk home and feed it to them.* *Other mothers choose to keep their frozen milk at home until they are ready to make a decision as to what to do with it.*	
When a mother wishes to collect her frozen expressed breast milk…. *Once you collect your milk,(we may also be able to arrange for this to be delivered on your behalf) there a some things to consider…….There are various options to consider* • *You could keep your milk at home in memory of your baby* • *You could keep your milk for a period of time and then discard it yourself* • *You could consider donating your milk to a human milk bank in memory of your baby……if this is something you might like to do, I can tell you a little bit more about it.*	
When a mother would like to donate her breastmilk…….. *This is something you might like to consider. Donor human milk is given to premature and vulnerable babies who are not able to have their own mother's milk. There is a robust screening process, which I can talk through with you, when you feel it's the right time. This is something some mothers have found very helpful, there are some stories directly from the parents. I appreciate and acknowledge that this isn't right for all families, but I'll share the information, so you can decide what's right for you.*	

Follow the QR link below to hear from a mum who donated milk in memory of her son after he was stillborn and her experience of their donation journey.

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