

The Memory Milk Gift Initiative: donation after loss



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At the Memory Milk Gift Initiative, we believe that every bereaved family across the UK should be given the opportunity to donate milk in memory of their baby.

Mission statement, Memory Milk Gift Initiative

In the UK, breast milk donation is not routinely offered as a choice in care after death of a baby. The Memory Milk Gift Initiative was founded in June 2021 with the aim of improving services offered to bereaved families donating to the Milk Bank at Chester. The first step was to set up parent and professional focus groups to gain feedback about our service and potential service improvements.

The Milk Bank at Chester

The Milk Bank at Chester (MBAC) is the largest NHS milk bank in England, supplying safe, screened, pasteurised donor milk to over 70 neonatal units across England and Wales. MBAC is a not-for-profit service run by the Countess of Chester Hospital, processing in excess of 2,000 litres of donor milk every year from approximately 250 donors.

Annually, around 5% of these donations are from bereaved families. Prior to the Memory Milk Gift Initiative, one bereaved family a month donated to the milk bank, predominantly through referrals from neonatal units. However, some families stumbled across the concept of milk donation and had to seek out the appropriate advice to self-refer. Donation after loss was not offered as routine. Since October 2021, we have supported 22 bereaved families to donate milk, a clear indication that this initiative is having an immediate impact on raising awareness of donation after loss.

Why donate?

“I always hoped that Bodhi would be a light in this sometimes dark world, and even in his passing there’s a chance yet he could bless more than just my family and friends’ lives.”

Holly Snook, Bodhi’s mum, March 2020.

Milk donation after loss presents itself in different ways:

- donation of milk expressed for a mother’s own baby who was receiving care in a hospital setting – this is the most common form of donation after loss
- continuing to express following the death of their baby
- initiation of lactation following a stillbirth or early neonatal death.

The Memory Milk Gift Initiative offers donors the following support throughout their donation journey:

- having a dedicated bereavement lead reduces the number of times that a family needs to share their story. This person is a point of contact for families and health professionals
- a pathway for donation after loss with scope for personalisation
- dedicated time to review each family weekly and ensure best practice.

One of our current donors was not aware of milk donation when her son was stillborn. She donated milk after her daughter was born two years later and said she wished she had been given the choice when her son passed away. We offered her the opportunity to donate the milk in her son’s memory.

“I hope that by donating my breast milk I may have helped prevent another family from experiencing my pain.”

This is just one example of how the pathway can be personalised to individual families.

Ayelet Oreg’s study, Milk donation after losing one’s baby, highlighted three main points:

1. Donor identity serves as a transformative identity while coping with loss.
2. Milk donation empowered bereaved mothers and helped them heal.
3. Bereaved mothers’ affiliation with milk banks strengthened their social networks.

The concept of a transformative identity while coping with loss is one that our donors talked about in our parent focus group. Identifying as a milk donor provided a purpose and encouraged self-care; especially for those donors who donated ongoing or initiated lactation. The main day-to-day benefits were for families to maintain a healthy lifestyle with limited caffeine and alcohol intake, and to keep in a routine of eating and keeping hydrated. Hygiene standards were also maintained.

Donating milk in memory of their baby empowered bereaved mothers, helping them to heal. Feedback from families who had donated after loss listed ‘helping others families avoid going through the trauma and pain that they had experienced’ as a main reason for wanting to donate milk. We received no negative feedback with regards to the donation experience.

This study helped us to recognise that here at Memory Milk Gift, we had the opportunity to do more. We could aim to strengthen these families’ social networks at a time that is often described as isolating and lonely. Feedback from our parent focus group reinforced the idea that families would like a safe space on social media to talk about their shared experiences. Francis’ mum, Abigail, said that she would like to share information about Francis, about his personality and why she chose to donate in his memory with other donors and recipients of donor milk (FIGURE 1).



FIGURE 1 Abby expressing milk to donate in memory of her son Francis.



FIGURE 2 The memory milk tree and wooden memory pebble, designed and hand painted by our Milk Process Operator, Kate Buckley.



On Instagram, @memorymilkgift has become a place where donors can share their story in their own words as every family is offered an Instagram ‘square’. Donors past and present have started to interact via the page and their shared experience of donation after loss.

In addition, we updated our website to give the Memory Milk Gift Initiative a more prominent position, making the information easier to find. Being aware of the desire for a safe space, this section of the website is completely separate, has more gentle branding and has no photographs of babies.

The professional focus group is developing, initially consisting of staff from the Countess of Chester and now including staff from units across the UK. Lecturers, charity CEOs and UKAMB (UK Association for Milk Banking) Chair Debbie Barnett MBE, have all joined the professional focus group too. We actively seek feedback from health professionals – if you would like to be involved please do get in touch.

On Twitter, @memorymilkgift is a platform to share our mission statement and nationwide goals with health professionals, baby loss charities and other milk banks.

Creating moments and making memories

There is an overwhelming sense of sadness among bereaved families that the opportunity for creating moments and memory making with their baby is limited.

By allowing families to donate in memory of their babies, we are allowing them the opportunity to add precious moments to their baby’s memory boxes. At Memory Milk Gift we offer four ways to acknowledge their milk donation and families can choose any combination of these options in their own time frame, during or after their donation journey.

1. Personalised thank you cards: these cards are hand personalised with the name of the baby and donors are able to request duplicate copies for family members.
2. Memory milk tree: the memory milk tree is hand painted on the wall at the Milk Bank at Chester. Every family is offered the opportunity to have their baby’s name included on the tree (**FIGURE 2**).

3. Wooden memory pebbles: wooden pebbles are hand painted in white and gold with a milk drop, ‘thank you’ and the baby’s name, varnished and presented in a velvet pouch. The wooden element ties in with the tree and these are smooth to touch and perfect for memory boxes. Our donors really do love these (**FIGURE 2**).

4. Instagram dedication squares: families active on social media are invited to share their baby’s story on a dedication square, the image used is a photograph of the personalised thank you card. The positive impact that this project has had can be seen in this quote from one of our donors:

“When George was born, I had to express milk, which we fed him through a syringe. When he got poorly, he was put on nil-by-mouth so the hospital froze my milk. Then when George passed, I was asked if I’d be willing to donate my milk to the milk bank, which gives milk to babies whose mums are poorly or can’t produce their own milk. I said yes and a few weeks later received a little pebble with George’s name on it and a thank you letter. Last month I got an email from the milk bank to say they were having a ‘memory milk tree’ painted at the Countess of Chester Hospital where they are based and did I want George’s name to be added. Of course, I said yes. I’m so happy that people other than us remember George and talk about him even though no one was able to meet him.”

Additional support for donors

It is our duty to recognise our limitations. We are not trained in grief counselling or as mental health professionals. We do, however, have regular contact with some of our bereaved donors for prolonged periods of time. Being able to signpost support throughout their donation journey – however long or short – is important and we are working closely with a local GP and national charities to ensure that this happens. It is also important to ensure that we work closely with the donor when it is time for their donation journey to end and to ensure that we have taken every step that a dependency on milk donation has not been created.

Good working relationships with the bereavement teams ensures that we can raise any wellbeing concerns immediately with a team

that has contact with the family. We have added a list of national charities to our website, which can offer support following the death of a child. The Memory Milk Gift Initiative is also linking with Our Sam SOS Baby Loss, the first comprehensive directory of support for anyone affected by baby loss (oursam.org.uk).

Milk donation after loss: variations across the UK

In September 2021, a survey was sent to all UK milk banks to gain an understanding of the services offered nationwide to bereaved families. Eight of 14 milk banks replied to the survey:

- All eight said they accept milk donations from bereaved donors if they feel it is appropriate. All agreed that they would direct donors to other milk banks if they were unable to accept a donation.
- All eight would accept a reduced donation amount from a bereaved donor.
- Only two offer bespoke options for memory making, and only one offers personalised memory making opportunities.
- The same two milk banks also offer opportunities for families to donate milk for research purposes when it is unsuitable for donation. For example, when a potential donor has taken medication incompatible with donation, milk can be used for a suitable research project or for in-house quality control with the donor's consent.

There is a clear lack of consistency as to how donations after loss are received and acknowledged. The Memory Milk Gift Initiative is striving to improve the services offered by working collaboratively with healthcare professionals, milk banks and families.

Every UK milk bank has been offered the opportunity to sign up to the Memory Milk Gift Initiative mission statement that 'Every bereaved family across the UK should be given the opportunity to donate their milk in memory of their baby'. By signing up, they are committing to offering families the

When discussing lactation suppression, 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 the 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

Speak to the milk bank about the most appropriate way to take blood samples for serological testing (bear in mind that some families will not want to return to hospital)*

Pass referral to the milk bank via telephone or email

TABLE 1 Best practice for donation after loss. *The Memory Milk Gift Initiative can provide approved postage boxes for blood samples for processing at the Countess of Chester Hospital.

opportunity to donate in memory of their baby. If a milk bank is unable to accept a donation for any reason, they can signpost the donor or referring health professional to the Memory Milk Gift Initiative. We will then direct them to an alternative milk bank with capacity or with the opportunity to donate for research projects. Working collaboratively going forward, we hope to commission at least three more memory milk trees; one in Scotland, one in Wales and one in the south of England.

Approaching donation after loss

When should a health professional discuss donation after loss? These families have already been given a huge amount of information, while experiencing trauma and have a huge emotional and physical journey ahead of them.

Having approached our parent focus group for advice on this – both those who had donated and those who hadn't been offered the opportunity to – the answer was blindingly simple. If the question about suppression of lactation is being asked, the alternative can and should be offered as standard (**TABLE 1**).

Next steps for the initiative

The Memory Milk Gift Initiative doesn't stop now. We still have work to do, and continual service improvement is a huge part of what the initiative stands for.

In order to raise awareness we need to provide the information to hospitals and make ourselves available to spend the time building relationships with these teams. The Memory Milk Gift Initiative has sent out 'bereavement packs' to over 40 hospitals and hospices across the UK and is continuing to send them to all UK neonatal units so that every hospital is equipped with the correct information to be able to offer the choice of donation. We are in the process of setting up a 'champion' scheme that staff members within neonatal units and bereavement teams can sign up to. We have been sharing the initiative at a wide variety of conferences, webinars, training sessions and forums including the National Neonatal Palliative Care Project (@neopallcare), the recent N3 Neonatal Nutrition Network winter meeting and the UKAMB bereavement webinar, From Tear Drops to Milk Drops.

Together, we can ensure that these families are being offered the choice they are entitled to and that their donations are acknowledged with the compassion they deserve.

Reference

1. **Oreg A.** Milk donation after losing one's baby: adopting a donor identity as a means of coping with loss. *Soc Sci Med* 2019;238:112519.

To learn more about the Memory Milk Gift Initiative and donation after loss, please take a look at our training videos on our YouTube channel:

www.youtube.com/watch?v=moJ7EwKnoeM

Here, you will also find Holly and Bodhi's story: Donation after loss; a parent's perspective.

Help wanted in compiling short quizzes for *Infant*

Infant is keen to encourage learning in a fun way with a short quiz in each issue of the journal.

Do you have any interesting case studies or ideas for inclusion?

Could you help us to compile questions to test knowledge of key aspects and best practice?

Please do get in touch; we'd love to hear your ideas: lisa@infantjournal.co.uk

