



**University
Hospitals Sussex**
NHS Foundation Trust

Lactation after loss

Neonatal

Patient information

Please accept our sincere condolences at this difficult time after the death of your baby.

We know that you have been working so hard to build up and maintain your milk supply, and your body will continue to produce this milk even after the death of your baby.

Each parent and each family's situation are unique.

For some parents, ending the milk production is important, and for others, donating milk can be a special way to honour their baby by helping others and channelling their grief, but it is not a choice that fits for every family.

This leaflet provides information on:

- How to safely suppress the production of your breast milk (called lactation)
- How to manage and ease symptoms of breast engorgement that you may feel at this time
- How to donate your milk should you wish
- How to create milk memories should you wish.

Should I try to stop my milk production?

If a milk supply has already been established, your body will continue to produce this milk for some time. It is very important that you do not stop the production of this milk abruptly as this could increase your risk of breast engorgement and mastitis.

Your breasts may feel fuller while you try to reduce your supply, but painful breast engorgement is not necessary and can be avoided.

What is engorgement?

Engorgement is when the breasts become swollen, firm and painful.

If too much milk fills your breast and isn't removed, engorgement can occur. Symptoms can include:

- Swelling and discomfort of the breasts, into the armpits.
- Taught, shiny skin.
- Redness to an area of the breast.

What is mastitis?

Sometimes, engorgement can lead to mastitis which is inflammation of the breast.

If left untreated, this can develop into a serious infection.

Signs and symptom include those already listed as above as well as:

- White or blood stained nipple discharge
- Flu like symptoms including chills, fever and fatigue.

If you are worried you may have mastitis please speak to your midwife, GP or health visitor as you may require antibiotics to treat the infection.

How can I help to relieve the symptoms of engorgement?

If you experience engorgement the following can be helpful to relieve your symptoms:

- Ice packs or cool gel packs can be useful, but it is best to avoid heat.
- Take regular pain relief such as paracetamol and ibuprofen.
- Wear a comfortable but supportive bra that does not restrict your circulation.
- Use breast pads inside your bra to help with breast milk leakage.
- Hand express a small amount for comfort if your breasts are feeling very full.

Binding or bandaging of breasts is not recommended.

How can I gradually stop my breasts from producing milk?

If you have an established milk supply, you will need to gradually reduce your pumping to avoid engorgement, plugged ducts and mastitis. Breasts remaining full for too long can be painful.

The following methods can be used to slowly stop pumping.

Choose the one that you feel will work best for you:

- Eliminate one pumping session every three days. This will allow your body to adjust downward gradually. When a pump session is dropped, space out the other sessions equally so the time between pumping gradually gets longer.

- Gradually increase intervals between pump sessions. If you usually pump every three hours, extend this to every four hours. After three days, increase the interval again. Gradually your breasts will stop feeling full and you will reach a stage where you no longer need to express to feel comfortable.
- Keep the number of pumping sessions the same but stop sooner. If you usually pump for 20 minutes at a time, stop after 15 minutes. After a few days only pump for 10 minutes. Gradually, you can begin just to express for a short time for comfort. Pumping as needed for comfort will not prolong the process. It will make it safer, more comfortable and prevents painful fullness, which could lead to mastitis.

Is there a medication I can take to help?

Yes, cabergoline is a medication which will help to reduce lactation, although it may not stop your milk supply completely, depending on how established your milk supply is at the time. Like all medicines there are some side effects, and it may not be suitable for everyone. Please speak to your midwife who will be able to support having this prescribed to you while you are an inpatient, it can also be prescribed by your GP once you are home.

Can I donate my milk?

You may wish to continue expressing to donate your milk, or you may wish to donate milk you have already expressed and has been frozen either at home or on the neonatal unit. If you would like to donate your milk, our nurses can help to guide you through this process.

Milk can be donated officially via milk banks and the UK has 15 milk banks. Information and contact details for them can be found at UKAMB, a charitable organisation that supports milk donation and NHS-recognised milk banks across the UK www.ukamb.org.

It may not always be possible, due to the eligibility criteria for milk donation, for milk to be donated for use in hospitals to feed babies. However, milk can still be donated and used, alternatively, for research to better understand breastmilk and its benefits.

UHSussex uses Hearts Milk Bank. You can contact the team at Hearts by email info@heartsmilkbank.org. You can also contact the milk bank by phone (**01442 505 020** between 9.30 am and 5:00 pm) The Hearts team will be ready to guide you through the process.

Once you have confirmation of donation, you will need to complete a questionnaire and fill in a consent form before a kit is then sent out to you for blood tests to be taken. This is to meet the national guidelines on milk donation. The blood tests can either be taken at your GP surgery or local phlebotomy centre.

Collection of the milk will then be arranged between the milk bank and yourselves. If you have milk stored at Trevor Mann Baby Unit (TMBU) it can be arranged for the courier to collect this on your behalf from the unit.

Milk needs to be less than 2 months old to be donated so that the milk bank has time to pasteurise it before 3 months.

Milk memories

As well as donating your milk, there are also other options you might want to consider if donating your milk is not appropriate for you.

- Keeping a container of your milk as a keepsake.
- Have your milk turned into a memento such as a pendant or a bead for a fee. You can find companies that will be able to help you with this online such as:

www.olivialaurajewellery.co.uk

www.milkdiamonds.co.uk

www.stuffedwithlove.co.uk

www.mamas-milk.co.uk

Where can I get further information and support?

It is vital that during your time of bereavement you are being well supported and within the University Hospital Sussex Foundation Trust you should have been signposted to the Bereavement Midwife for RSCH/PRH and/or the Child Death Review Keyworker on TMBU. If you do not have the contact details for either of these services please contact Maternity or TMBU who will be happy to provide you with the necessary contact details.

National Support

Stillbirth and Neonatal Death Charity

www.uk-sands.org Helpline: 0207 4365881

Child Bereavement UK

www.childbereavementuk.org Telephone: 0800 0288840

National Breastfeeding Helpline

www.nationalbreastfeedinghelpline.org.uk

Telephone: **0300 100 0212**

Children of Jannah

www.childrenofjannah.com

Jewish Bereavement Counselling Service

www.jbcs.org.uk Telephone: **0208 9513881**

Legacy of Leo (LGBT resources and experiences)

www.thelegacyofleo.com/lgbt-baby-loss/

Further Reading

**Nancy Morbacher (2021) Breastfeeding Answers Pocket Guide.
2nd Edition**

UKAMB. www.ukamb.org

**BAPM (2022) Lactation and Loss: Management of lactation
following the death of a baby**

www.bapm.org/resources/lactation-and-loss-management-of-lactation-following-the-death-of-a-baby

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