

# St Mary's Hospital's family clinic HIV and breastfeeding your baby Information for mothers who plan to breastfeed

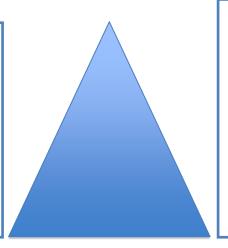
# Introduction

The safest way for a mother living with HIV in the UK to feed her baby is to bottle feed using formula milk.

If you are on treatment with an undetectable viral load and choose to breastfeed your baby we can help you make it as safe as possible but it will not be as safe as using formula milk. Until we know more about the safety of breastfeeding on antiretroviral therapy, always protect your baby using '**The Safer Triangle**' below:

### No virus

If the HIV virus in your blood is detectable, there will be HIV in your breast milk which means HIV will enter your baby's body when feeding. You should only breastfeed if your HIV is undetectable.



#### Happy tums

Diarrhoea and vomiting show that a tummy is irritated. If your baby's tummy is irritated it may be more likely that HIV will cross into their blood steam and infect your baby. If your tummy is irritated you may not absorb your HIV medication properly. Only breastfeed if both of you have a happy tummy.

### Healthy breasts for mums

There may be HIV in your breast milk if your nipples are cracked, bleeding, have thrush, develop an infection or if you have mastitis. Only breastfeed if your breasts are healthy.

# The Safer Triangle means No virus + happy tums + healthy breasts for mums

Only breastfeed if your HIV is undetectable **and** both you and your baby are free from tummy problems **and** your breasts and nipples are healthy with no signs of infection.

**If HIV virus becomes detectable in your blood:** Stop breastfeeding and start using formula milk. Only use formula milk until you have spoken with your HIV clinic. Do not use breast milk that you have expressed and stored.

**If your baby has diarrhoea or is vomiting:** Feed your baby with formula milk only. Keep feeding them formula milk even after their tummy is better.

If you have diarrhoea or vomiting, or your breasts have an injury or infection: Stop breastfeeding and feed your baby with formula milk or use breast milk that you expressed more than 2 days (48hrs) before your tummy or breast problem began. If your baby has formula milk while you are ill, continue feeding them formula milk only. If your baby did not have formula milk you can start breastfeeding again 2 days (48hrs) after your breast problem has healed. If you had tummy problems you must contact your HIV clinic before breastfeeding.

# Four golden rules

These 4 golden rules will help to protect your baby from HIV while breastfeeding:

#### (1) Taking your meds = giving your love

The HIV medicines you take protect your baby as well as you. You need to be 'undetectable', with no HIV detectable in your blood, to breastfeed your baby. The only way to do this is to take your HIV medications at the right time every day.

Every day you are already caring for your baby keeping them clean, warm and comforted. Taking your HIV medication as perfectly as possible is just another part of the love that you are already giving your child.

#### (2) Short and sweet

The fewer breastfeeds your baby has, the lower the chance of him or her becoming HIV positive. Even if you are taking your HIV medication, your baby has double the chance of becoming infected with HIV if you breastfeed for 12 months rather than stopping before he or she is 6 months old.

If your baby doesn't like the bottle at first, try asking someone else to give it to them– what your baby won't accept from mum he or she may take from someone else!

### (3) Breast milk only

If you choose to breastfeed, while your baby is under 6 months old, you should give breast milk **only** and no other food or drinks. This is known as exclusive breastfeeding. Giving breast milk and other foods may irritate the young (younger than 6 month old) baby's tummy and increase the risk of HIV infection. You can still give your young baby vitamins or prescribed medicines. Your baby can also have bottles of your own expressed breast milk. We recommend starting to do this early on, so your new baby gets used to the bottle as well as the breast.

### (4) Be prepared

Breastfeeding doesn't always go to plan. A mother living with HIV faces the same challenges during breastfeeding as any mother. Living with HIV means these situations need to be managed with extra planning. Advice for a breastfeeding mother who does not have HIV may not be correct for you and your baby. We encourage you to tell your community midwife about your HIV to help make sure they are giving you the right advice for you and your baby. If you are uncertain about something ask your specialist midwife, your specialist children's nurses, or your HIV doctor.

# Get comfortable

Ask your specialist midwife and community midwife for help with breastfeeding positions. Good feeding positions will reduce the chance of injuries to your nipple. An injured nipple or inflamed breast (known as mastitis) can increase the amount of HIV in your milk.

# Expressing milk

Expressing milk means gently squeezing or pumping your milk from your breast into a sterile container to use either right away or save for later.

One of the most useful ways to prepare for any breastfeeding difficulties is to express and freeze your breast milk while your breasts and tummy are healthy and your viral load is undetectable.

You can express your milk by hand into a cup that has been boiled in water for 10 minutes and then allowed to cool. You can also use a breast pump. You can rent one from the hospital or buy one from places such as Boots or Argos. Pumps can be hand controlled or electric and range from £10 to over £200.

Your milk can be safely stored in a sterilised container or individual pre-sterilised plastic breast milk bags (about £7.50 for 30). Write the date and the amount of milk on the container before you store it.

You can keep your expressed milk:

- in the fridge for up to 5 days at 4 degrees centigrade or lower. Using a fridge thermometer (about £5 from places like Tesco or Currys) is the best way to make sure your milk is kept at the right temperature
- for 2 weeks in the ice compartment of a fridge
- for up to 6 months frozen in a freezer

Ask your community midwife for more advice on expressing and storing milk.

## Formula feeds for back-up

If one side of the Safer Triangle breaks (No virus + happy tums + healthy breasts for mums) you may need to stop breastfeeding and give your baby formula milk. Even if you are breastfeeding, keep a small supply of formula milk at home for your baby in case of an emergency.

### You will need:

- the right stage formula milk for your baby (stage 1 for 0–6 months, stage 2 follow on milk for 6–12 months)
- 2 bottles or more
- 2 teats or more
- a method to sterilize the bottles and teats

# Introducing your baby to food

When babies are 6 months old, they are ready to start weaning and can gradually have simple foods along with their breast milk or formula. If you are breastfeeding while living with HIV, do not introduce your baby to any other food, including purees or cereal, before they are 6 months old. If your baby begins weaning early (before they are 6 months old) you must stop breastfeeding and switch to formula milk.

When your baby is 6 months or older, you can stop breastfeeding and move him or her onto formula and then food, or continue breastfeeding while introducing your baby to food. Good first foods are cooled, mashed vegetables like potatoes or carrots, soft fruits or baby cereals mixed with formula milk. You should follow the same weaning advice from your health visitor and the NHS as all mothers and babies in the UK.

If you continue to breastfeed after your baby has started food your HIV viral load must always be undetectable. If your viral load becomes detectable you need to stop breastfeeding. Babies tummies may be more irritated during weaning. If your baby develops diarrhoea or vomiting you must stop breastfeeding.

Using only formula milk while weaning means your baby will get the vitamins and calories he or she needs to grow without any risk of HIV infection. Until we learn more from breastfeeding mothers living with HIV, using formula milk and no breast milk is still the safest way to feed your weaning baby in the UK.

#### How to stop breastfeeding

Abrupt weaning from breastfeeding to formula and / or solids can be avoided, as long as your HIV viral load remains fully suppressed. However, if your viral load becomes detectable you will have to stop breastfeeding and only use formula milk to protect your baby from HIV. This can make your breasts feel full of milk and uncomfortable. It may also increase your risk of a breast infection. Two things can help:

(1) Hand expressing just enough milk to keep your breasts comfortable. Each day, make the amount you express less and less, and the length of time between when you are expressing longer and longer. Do 1 less session every 2 to 3 days, depending on how your breasts feel. If you normally breastfeed your baby 6 times a day reduce this to 5 times a day, wait a day or 2 and reduce this to 4 times a day. Keep going until you have stopped breastfeeding. This will help your breasts to gradually stop making so much milk.

(2) Cabergoline is a tablet that stops your body making breast milk. You may need to take 1 tablet once or a smaller dose 4 times over 2 days. This can make ending breastfeeding more comfortable for you. Ask your HIV clinic or your GP to prescribe cabergoline for you.

You can keep this medicine at home for when you want to stop breastfeeding.

# Help with breastfeeding problems for women living with HIV

If you have a problem breastfeeding and this leaflet does not help and you cannot get hold of a healthcare professional who understands HIV and breastfeeding, use the Safer Triangle and ask your community midwife or GP for advice.

Once you begin feeding your baby formula milk **do not** go back to breastfeeding.

### Mastitis

When milk stays in the breast for longer than usual, or the whole breast isn't being fully emptied, you can get a blocked milk duct. This can become inflamed and / or infected. This is called mastitis. Mastitis is very common -1 in 10 and up to 1 in 3 breastfeeding women develops it. Speak with your community midwife about how to prevent and treat a blocked duct so it does not become mastitis.

### Symptoms of mastitis

- A red, swollen area on your breast that may feel hot and painful to touch
- A breast lump or area of hardness on your breast
- A burning pain in your breast that may be continuous or may only occur when you are breastfeeding
- Nipple discharge, which may be white or contain streaks of blood
- You may also feel achy, have a high temperature, chills and be very tired

Mastitis can develop quickly. See your GP or go to A&E if you have symptoms of mastitis to avoid a breast abscess (a build-up of pus) forming.

### How to manage mastitis

Mastitis causes the amount of virus in breast milk to increase. If you develop mastitis, do not breastfeed your baby. The safest thing you can do if you develop mastitis is to stop breastfeeding and change to formula milk.

- Express and throw away milk regularly from both breasts
- Throw away any milk expressed from the 2 days before the breast became sore
- Your doctor may give you antibiotics. Some will enter your breast milk. If you continue to breastfeed your baby against advice, the antibiotics may cause your baby to have diarrhoea. This is a sign that your baby's tummy is irritated and can increase the risk that HIV will enter your baby's body
- Rest and drink lots of fluids
- You can use paracetamol or ibuprofen. Do not use aspirin if breastfeeding

- Avoid tight clothes or bras
- Warm baths and directing a hot shower onto the affected breast can help

#### Feeding your baby after the mastitis has healed

- If you start formula feeding, do not go back to breastfeeding. Continue to only feed your baby formula milk even after the mastitis has healed
- If you had enough stored breast milk to feed your baby with while you were unwell, and you did not feed your baby formula milk, you can start breastfeeding again 2 days (48hrs) after your mastitis has completely healed
- If your baby has runny poos or other signs of tummy irritation do not feed him or her with any breast milk neither stored expressed milk, nor straight from your breast. Continue to feed your baby with formula milk after their tummy irritation has improved

# Cracked or bleeding nipples

Sore and injured nipples are usually because the baby is not latching onto the nipple well. Ask your community midwife or health visitor for help with this.

Irritated and broken skin can allow your blood to get into your breast milk. This could increase the chances of your baby being infected with HIV.

- Do not feed your baby from the sore breast while the nipple is cracked
- Hand express or pump milk from the sore breast and throw this milk away
- Do not feed you baby from the sore breast until the breast has healed and has been blood and pain free for at least 2 days (48hrs)
- Breastfeed your baby from the other breast
- If both breasts are cracked and sore even if there is no blood do not breastfeed your baby. Use your supply of stored expressed milk instead
- If you do not have enough stored expressed milk, feed your baby using formula milk

### Feeding your baby after cracked nipples have healed

If you start formula feeding, do not go back to breastfeeding. Continue to only feed your baby formula milk.

If you had enough stored expressed breast milk to feed your baby with while your nipples were cracked or irritated and you did not feed your baby formula, you can breastfeed again 2 days (48hrs) after your nipples are completely healed.

## Thrush: Candida yeast infection

Thrush is a yeast infection in your nipple. It can be passed from mother to baby and baby to mother. Sore and cracked nipples are more likely to develop thrush and nipples with thrush are more likely to stay sore and cracked. You are more likely to develop nipple thrush if you, or your baby, have been on antibiotics. If you, or your baby, have signs of thrush you are likely to pass it back and forth to each other until both of you are successfully treated.

### Symptoms of nipple thrush in the mother

- Breastfeeding is painful in both breasts, when previously it felt ok
- It is less likely to be nipple thrush if the pain is only on 1 side, you have a fever, or there is a warm, red patch on one of your breasts

### Managing nipple thrush

- Treat thrush with anti-fungal medicine for you and your baby and painkillers such as paracetamol or ibuprofen (not aspirin). Your GP can prescribe this for you
- If your nipple is cracked or bleeding do not breastfeed from the sore breast
- You can continue to breastfeed from the healthy breast, although it is likely that both nipples will have thrush
- Use your supply of frozen milk instead
- If you do not have enough frozen milk, feed your baby using formula milk
- Express and throw away milk from the sore breast until 48hrs after it has recovered

### Feeding your baby after the nipple thrush has healed

- If you start formula feeding, do not go back to breastfeeding. Continue to only feed your baby formula milk
- If you had enough stored expressed breast milk to feed your baby with while your nipples were cracked or irritated, and did not feed your baby formula milk, you can start breastfeeding again 2 days (48hrs) after your nipples are completely healed

# If you have diarrhoea and vomiting

You may not absorb your HIV medicine well if you have diarrhoea or are vomiting. This may cause a temporary increase in the amount of HIV in your breast milk.

- Do not breastfeed your baby if you have diarrhoea or are vomiting because you may not have absorbed enough of your anti-retroviral medicine
- Use your supply of stored expressed breast milk instead
- Express your milk and throw it away until at least 2 days (48hrs) after you last had diarrhoea or vomited
- Tell your clinic team, as they may want to check that the virus in your blood is still undetectable
- Your HIV clinic team may ask you not to breastfeed your baby and to throw away any expressed breast milk until they have been able to check the amount of virus in your blood
- If you do not have enough stored expressed breast milk then feed your baby with formula milk
- If you start formula feeding, do not go back to breastfeeding. Continue to only feed your baby formula milk
- If you had enough stored expressed breast milk to feed your baby with while you were unwell and did not feed your baby formula, you may be able to breastfeed again once you have spoken with your HIV clinic team

## Diarrhoea and vomiting in your baby

If your baby has diarrhoea or is vomiting, it is safer to feed them formula milk. Diarrhoea and vomiting are signs that your baby's tummy and gut are irritated. This will make it more likely that any HIV in your breast milk can enter your baby's bloodstream and cause infection.

Start formula feeding and do not go back to breastfeeding. Continue to only feed your baby formula milk.

# If your baby is not putting on weight

You may be told to give your baby extra feeds of formula milk. Start formula feeding and do not go back to breastfeeding. Continue to only feed your baby formula milk.

# If HIV becomes detectable in your blood (detectable viral load)

Stop breastfeeding and start formula milk feeding.

Please ask us for a copy of our 'Breastfeeding your new baby' leaflet for more information about possible financial support towards the cost of formula feeding.

### And finally...

We are learning more all the time about how to keep mothers and babies with HIV healthy. You may have a question for which we do not yet have a definite answer. If this happens we will use our experience to guide you. We will tell you when new scientific evidence is available. If you have a question and cannot reach us, use the Safer Triangle.

## **Contact details**

#### Children's clinical nurse specialists

Telephone: 020 3312 6946 Email: family.clinic@nhs.net

#### **Specialist midwife**

Telephone number: 020 3313 5179 Bleep 020 3311 1000 pager number 9601

### Mentor Mother at Positively UK

www.positivelyuk.org/pregnancy/ Telephone: 020 7713 0444 Email: hrogers@positivelyuk.org

# Helplines

- National Breastfeeding Helpline: 0300 100 0212
- Association of Breastfeeding Mothers: 0300 100 0212
- La Leche League find your local number here: www.laleche.org.uk/call
- National Childbirth Trust (NCT): 0300 330 0700

## How do I make a comment about my visit?

We aim to provide the best possible service and staff will be happy to answer any of the questions you may have. If you have any **suggestions** or **comments** about your visit, please either speak to a member of staff or contact the patient advice and liaison service (**PALS**) on **020 3313 0088** (Charing Cross, Hammersmith and Queen Charlotte's & Chelsea hospitals), or **020 3312 7777** (St Mary's and Western Eye hospitals). You can also email PALS at **imperial.pals@nhs.net.** The PALS team will listen to your concerns, suggestions or queries and is often able to help solve problems on your behalf.

Alternatively, you may wish to complain by contacting our complaints department:

Complaints department Fourth floor Salton House St Mary's Hospital Praed Street London W2 1NY

Email: ICHC-tr.Complaints@nhs.net

Telephone: 020 3312 1337 / 1349

## Alternative formats

This leaflet can be provided on request in large print or easy read, as a sound recording, in Braille or in alternative languages. Please email the communications team: **imperial.patient.information@nhs.net** 

## Wi-fi

We have a free wi-fi service for basic filtered browsing and a premium wi-fi service (requiring payment) at each of our five hospitals. Look for WiFiSPARK\_FREE or WiFiSPARK\_PREMIUM

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