# General information on infant feeding for parents living with HIV

The British HIV Association recommends that the safest way for a parent with HIV to feed their baby is with formula milk, as there is absolutely no risk of HIV transmission after birth

HIV health workers understand that HIV may not be the only thing you need to think about when feeding your new baby. We have put together information that will help you make an informed decision about feeding your baby. Whatever you decide, if you are on good HIV treatment, your clinic team will support your decision. Let your HIV care team know if you decide to breast/chestfeed your baby; they can then work with you to help make this as safe as possible, even though it will still not be as safe as feeding your baby with formula.

The most important things are to keep taking your medications and attending appointments, to enjoy this time with your new baby, and to get in touch if you have any questions or difficulties.

#### If you are considering breast/chestfeeding your baby

- You need to have an undetectable viral load and be taking your anti-HIV medication at the right time every day.
- If you breast/chestfeed your baby, they should ideally only have breast/chest milk for the first 6 months, but you can also give formula milk if the baby needs it occasionally as a top up (e.g. when you are establishing breastfeeding). You must not give the baby solids or any other foods before 6 months of age.
- There are times when the risk of passing HIV to your baby can increase. These include if you have a detectable viral load, mastitis, cracked nipples, diarrhoea or vomiting or if your baby is sick with diarrhoea and/or vomiting. You should not breast/chestfeed your baby at these times. You will need to contact your HIV clinic team for further advice.
- Make sure to talk to the HIV team looking after you and your baby so that they know about your decision to breast/chestfeed, and so they can support you to make it as safe as possible for your baby. If your HIV clinic team has not supported anyone to breast/chestfeed before, see details on page 5 of organisations that can support you.

If you follow this guidance for 'safer breast/chestfeeding', we can fully support you to breast/chestfeed your baby.

#### Is your breast/chest milk best for your baby?

#### **Background**

- If you formula feed your baby there is no risk of getting HIV after birth.
- The longer a baby is breast/chestfed, the higher the risk the baby will get HIV.
- There has been very little research on the risk of HIV with breast/chestfeeding in the UK.

The research we have on HIV and breast/chestfeeding in parents on HIV treatment comes from outside the UK. The largest clinical trial is the PROMISE trial, undertaken in Africa and India. In this study, over time, the number of infants who got HIV, according to how long they were breastfed was:

After 6 months of breastfeeding: 3 in 1000 infants After 9 months of breastfeeding: 6 in 1000 infants After 12 months of breastfeeding: 7 in 1000 infants After 18 months of breastfeeding: 7 in 1000 infants After 24 months of breastfeeding: 7 in 1000 infants

Reference: Prevention of HIV-1 transmission through breastfeeding: efficacy and safety of maternal antiretroviral therapy versus infant nevirapine prophylaxis for duration of breastfeeding in HIV-1-infected women with high CD4 cell count (IMPAACT PROMISE): a randomized, open label, clinical trial. <u>J Acquir Immune Defic Syndr 2018</u>; 77: 383–392.

Some parents and babies find breast/chestfeeding straightforward. For others (regardless of whether they are living with HIV) it can be difficult especially when getting started. You might have read about the benefits of breast/chestfeeding for the parent and baby. These benefits are real but, on balance, less important than the harm from acquiring HIV.

In resource-poor areas (e.g. parts of Africa and Asia) it is safest for parents with HIV to breast/chestfeed their babies. This is because water may be unclean, there might not be ways to sterilise bottles, and baby formula may not always be available or affordable. There is more risk that a formula-fed baby in these areas will die from infections from dirty water or not having enough food, than a breastfed baby will die from HIV infection.

In the UK, a resource-rich country, the situation is different. Your baby is very unlikely to get an infection from the water used in formula feeding but might still have a risk of getting HIV if you breast/chestfeed, even if this risk is very small.

## Formula feeding is very common in the UK

Overall, more than 8 out of 10 parents in the UK are feeding their babies with formula milk by the time the baby is 3 months old, although rates differ among different ethnic groups. Once the baby is 6 months old, only 1 in 100 UK parents are still giving their baby breast/chest milk only. Overall, if a parent is not breast/chestfeeding in the UK, people will not think it is unusual and are unlikely to think it has anything to do with being HIV positive. If you are formula feeding, having a lot of eye contact and skin-to-skin contact with your baby will still give you and your baby a very close bond.

## **Appointments**

If you decide to breast/chestfeed, you and your baby will need to have monthly appointments to check your baby's health, with blood tests to make sure the baby remains HIV negative.

The number of blood tests and checks you and your baby will have depends on how you decide to feed your baby

#### Formula-fed baby: HIV viral load tests

Blood tests for the parent and baby at birth Blood tests for the baby at 6 weeks and 12 weeks after birth

## Breastfed baby: HIV viral load tests

Blood tests for the parent and baby at birth

Blood tests for the parent and baby every 4 weeks during breast/chestfeeding

Blood tests for the baby at 4 weeks and 8 weeks after stopping breast/chestfeeding

All infants will also have an HIV antibody blood test at 22–24 months of age to confirm they have lost all HIV antibodies from the blood

## Your medicines in your breast/chest milk

Your anti-HIV medication may get into your breast/chest milk. How much will depend on what you are taking and how your body absorbs the drug, but usually it is only a tiny amount which will not have any effect on your baby. There is more research going on into this.

Having a new baby takes up a lot of time and energy; make sure you are taking (adhering to) your anti-HIV medication every day at the correct time and getting your blood virus levels (viral load) checked. Keeping the amount of virus in your blood undetectable (asleep) will make it far less likely that the HIV will pass into your baby through breast/chestfeeding.

There is a chance that if your baby gets HIV through breast/chestfeeding the virus may be resistant to medicine you were taking, and this may not work for your baby. This is important because HIV doctors will not have as many medicines to treat their HIV with in the future.

## Only your milk

**'Exclusively breast/chestfeeding'** means your baby is receiving only your breast/chest milk, and no other food, drink or baby formula.

'Mixed feeding' is where babies receive formula milk and/or solid foods as well as breast/chest milk. Giving solid foods before 6 months of age, in addition to breast/chest milk, at least doubles the risk of babies getting HIV. Therefore this is NOT recommended. The lining of the baby's intestines is not ready to take solid foods before 6 months of age, and this may cause inflammation of the gut which can increase the risk of HIV passing to the baby.

If you choose to breast/chest feed, ideally you must feed your baby your breast/chest milk 'exclusively'. However, there is evidence from African studies that breastfed babies under 6 months of age who received formula milk as well (also known as 'combi feeding' with both breast/chest and formula milks) did not have an increased risk of HIV. So if your breast/chestfed baby needs formula milk in addition to your milk for an occasional top up, this is fine. But, you should **never** give your baby solid foods (cereals, pureed fruits/vegetables etc) under 6 months of age, if you are breast/chestfeeding. Do not accept advice to wean early; do not start to wean before your baby is 6 months old.

When your baby is 6 months or older they will start eating solid food and will no longer be exclusively breast/chestfed. Ideally, you should stop breast/chest milk and move your baby onto formula and only then add solid foods. Until we learn more from breast/chestfeeding parents living with HIV in the UK, using formula milk and not breast/chest milk is probably the safest way to feed your baby while weaning. Sometimes it is not easy to stop breast/chestfeeding, so it is good to have a plan. Introducing bottles of expressed milk from an early age to get the baby used to the teat can help, as well as getting advice from a lactation consultant or your clinic team.

# How long should I breast/chestfeed my baby?

The shorter the length of time you breast/chestfeed your baby, the lower the risk that they will get HIV. If you decide to breast/chestfeed, it is a good idea to plan when you will change to formula, but we do not recommend breast/chestfeeding beyond 6 months.

# Safeguarding concerns

If you are taking your anti-HIV medication, have an undetectable viral load and are adhering to the 'safer breast/chestfeeding' guidance, we will support you to breast/chestfeed your baby. If you are not taking your anti-HIV medication every day, and your virus is detectable in the blood and therefore also your milk, and you are still breast/chestfeeding, the risk of passing on HIV to your baby becomes much higher. This could put your baby at enough risk that Children and Family Services may need to be called to help keep the baby as safe as possible. We want to avoid this, and want to work with you to care for your baby in the safest way.

## Deciding what you want to do

All new parents need to make decisions about how they want to feed their babies. Having HIV just adds a few more things to consider. Whatever you decide, agree with your partner what you will say to friends and family; everyone is more likely to accept your reasons if they are always the same.

This may be an easy or a complicated decision for you. You may know exactly what you want or you may have more things you want to know. Discuss these with your midwife, doctor, paediatric nurses, Mentor Mothers and peer supporters. Take time to make your decision. Do not feel pressured by others.

Your clinic team are here for you and your new baby, to help and support you, however you decide to feed your baby. If you feel you would like more support with making this decision, consider talking to Mentor Mothers at Positively UK who are very happy to talk things through with you (Helen on 020 7713 0444 or email hrogers@positivelyuk.org).

#### Some parents choose to breast/chestfeed for the following reasons:

'I wanted to feel close to my baby'

'I know there are health benefits to breastfeeding'

'I breastfed my last baby and he is fine'

'Formula is too expensive'

'My mother-in-law keeps making me breastfeed'

'My husband does not know about my HIV and I do not want him to find out'

'I was told where I used to live that breastfeeding while taking treatment is safe'

'Breastfeeding is more convenient'

My baby and I are going to a country where and I can't always get formula and do not know if the water is clean'

If you decide to formula feed, people may sometimes ask, or even pressure, you about why you are not breast/ chestfeeding.

Peer supporter (from Mentor Mothers; HIV+ 25 years) suggested these responses if someone asks why you are bottle feeding:

'I don't want to risk passing on HIV or my meds to my baby'

'Breastfeeding just didn't work for us'.

'I am taking antibiotics'

'He started off on formula so we just stuck with it'

'The health visitor said she is doing great and to just keep doing what I am doing'

'This means her dad can help out more'

'I was told skin-to-skin is just as good'

'It's a personal choice'

'I have inverted/painful nipples'

'I had problems with breastfeeding previously'

I prefer the privacy'

## Financial support for formula feeding

You will need bottles and teats to bottle feed and a way to clean and sterilise them. You can use a bottle brush with a bottle steriliser or sterilising chemicals, or boil the equipment in water for 10 minutes.

It is important to make up your baby's bottle with the correct amount of water and formula for their age. That is how you will be certain they will be getting the right amount of vitamins and nutrients, as milk continues to be the baby's main source of nutrition until about 1 year of age. In some areas parents with HIV can obtain free formula milk for the first 6 months; please check with your clinic team, and see below for other support options.

Support	What it offers	You are entitled to this if:
Sure-Start Maternity Grant	A one-off payment of £500	You are expecting your first child, or twins or triplets and already have children, or you or your partner are receiving certain benefits
Healthy Start vouchers	You can use these for food, milk and baby formula at supermarkets, chemists and corner shops	You are receiving Income Support, Jobseeker's Allowance or Child Tax Credit, or are under 18 years old

#### **Support**

CHIVA – UK and Ireland (via referral from clinic or charity): https://www.chiva.org.uk/

Local HIV support

Glasgow – Waverley Care: <a href="https://www.waverleycare.org/">https://www.waverleycare.org/</a> Leeds – Skyline: <a href="https://thebha.org.uk/support-leeds/">https://thebha.org.uk/support-leeds/</a> Manchester –George House Trust: <a href="https://ght.org.uk/">https://ght.org.uk/</a>

Sussex – The Sussex Beacon: <a href="https://www.sussexbeacon.org.uk/">https://www.sussexbeacon.org.uk/</a>

London – The Food Chain: <a href="https://www.foodchain.org.uk/">https://www.foodchain.org.uk/</a>

Mentor Mothers at Positively UK: <a href="http://positivelyuk.org/pregnancy/">http://positivelyuk.org/pregnancy/</a>

Helen Rogers: Telephone number: 020 7713 0444; Email address: hrogers@positivelyuk.org

For other organisations that can provide basic breastfeeding advice, see NHS choices 'Breastfeeding Help and Support' for a list of websites and helplines (<a href="https://www.nhs.uk/conditions/baby/breastfeeding-and-bottle-feeding/breastfeeding/help-and-support/">https://www.nhs.uk/conditions/baby/breastfeeding-and-bottle-feeding/breastfeeding/help-and-support/</a>).

#### **Helplines**

National Breastfeeding Helpline – 0300 100 0212 Association of Breastfeeding Mothers – 0300 330 5453 La Leche League – 0345 120 2918 National Childbirth Trust (NCT) – 0300 330 0700

#### **Authors**

Yvonne Gilleece, Laura Byrne, Alasdair Bamford, Nell Freeman-Romilly, Hermione Lyall, Paula Seery, Shema Tariq January 2023