General information on infant feeding for women living with HIV

The British HIV Association recommends that the safest way for a mother with HIV to feed her baby is with formula milk, as there is absolutely no risk of HIV transmission at all after birth (BHIVA 2018)

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, you will not be judged. Let your HIV care team know if you decide to breastfeed 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 you can do are to keep up with your medications and appointments, enjoy this time with your new baby, and get in touch if you have any questions or difficulties.

If you are considering breastfeeding your baby

- You need to have an undetectable viral load and be taking your anti-retroviral therapy treatment at the right time every day.
- If you breastfeed your baby, he or she should only have breastmilk for the first 6 months, and not formula or cow’s milk too.
- 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 has diarrhoea or vomiting. You should not breastfeed your baby at these times. You will need to contact your HIV clinic for further advice on breastfeeding.
- The HIV team looking after you and your baby should know about your decision to breastfeed so that they can help you make it as safe as possible for your baby.
- Following the guidance above means you are following the plan for ‘Safer Breastfeeding’ and we will support you to breastfeed your baby.

Background

- If you formula feed your baby there is no risk of HIV infection after birth.
- The longer a baby is breast fed, the more likely he or she will be to get HIV.
- The research we have on HIV and breastfeeding comes from outside of the UK.
- There has been no research on HIV and breastfeeding in the UK

Is breast best for your baby?

If 100 mothers with HIV breastfeed their babies for a year while having an undetectable viral load in the blood:

1–2 babies may become HIV positive

If 100 mothers with HIV formula feed their babies:

0 babies will become HIV positive
Some mothers and babies find breastfeeding straightforward. For others it can be difficult. You might have read about benefits of breastfeeding for the mother and the baby. These benefits are real, but on balance, less important than the harm that HIV can do.

In resource-poor areas (e.g. parts of Africa and Asia) it is safest for mothers with HIV to breastfeed their babies. This is because water may be unclean, there might not be ways to sterilise the baby 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 future.

In the UK, things are different. Your baby is unlikely to get an infection from the water used in formula feeding, but if you breastfeed, your baby might still get HIV.

**Formula feeding is very common in the UK**

More than 8 out of 10 mothers in the UK are feeding their babies with formula milk by the time the baby is 3 months old. Once the baby is 6 months old, only 1 in 100 UK mothers are giving their baby breast milk only. If a mother is not breastfeeding 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 lots of eye contact and skin-to-skin contact with your baby will still give you and your baby a very close bond.

**Appointments**

You and your baby will have extra appointments and more blood tests if you decide to breastfeed. This is to make sure there is no HIV detected in your blood and to check your baby's health and make sure she or he 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:**

<table>
<thead>
<tr>
<th>Timing of Bloodtests</th>
<th>Breastfeeding woman</th>
<th>Breastfeeding baby</th>
<th>Formula fed baby</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>At birth</strong></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td><strong>Every 4 weeks as long as you are breastfeeding</strong></td>
<td>For example: Six blood tests if breastfeeding for 6 months (1 per month)</td>
<td>For example: Six blood tests if breastfeeding for 6 months (1 per month)</td>
<td></td>
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<tr>
<td><strong>6 weeks after birth</strong></td>
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<tr>
<td><strong>12 weeks after birth</strong></td>
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<tr>
<td><strong>4 weeks after you have stopped breastfeeding</strong></td>
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<tr>
<td><strong>8 weeks after you have stopped breastfeeding</strong></td>
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</table>
Your medicines in your breast milk

Your HIV medication can get into your breast milk. How much will depend on what you are taking and how your body absorbs the drug.

Your HIV drugs will not usually hurt your baby. They will cause much less harm than if you stop taking your medications and the amount of HIV in your body increases.

Having a new baby can disrupt the best schedule. Make sure you are taking (adhering to) your HIV medicines every day at the correct time and getting your blood virus levels checked. Keeping the amount of virus in your blood undetectable will make it less likely the HIV will pass into your baby through breastfeeding.

There is a chance that if your baby gets passed HIV through breastfeeding the type of medicine you were taking may not work for your baby. This is important because children’s HIV doctors will not have as many medicines to treat their HIV with in the future.

Only breast milk

‘Exclusively breastfeeding’ means your baby is receiving only breast milk, and no other food, drink or baby formula. Giving other foods and types of feeds, in addition to breast milk, has been shown to double the risk for some babies of becoming infected with HIV. If you choose to breastfeed, you must breastfeed your baby ‘exclusively’. When you are ready to stop breastfeeding exclusively you can switch to formula milk if under 12 months, or cow’s milk if your baby is over 12 months of age.

When your baby is 6 months or older he or she will start eating food and will no longer be exclusively breastfeeding. You can stop breastfeeding and move your baby onto formula and then food. Until we learn more from breastfeeding mothers living with HIV, using formula milk and no breast milk is the safest way to feed your weaning baby in the UK.

Length of time

The shorter the length of time you breastfeed your baby, the less chance they will have of getting HIV. If you decide to breastfeed, it may be helpful to have an idea of when you will change to formula.

Money

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 calories. You may need to spend about £250 to feed your baby for the first 6 months. From 6 months you will be introducing solid foods and starting to reduce the amount of formula you are giving your baby.

Formula and bottle 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 (approx. £25), sterilising chemicals (approx. £1.50 for 3 months) or boil the equipment in water for 10 minutes.

You may want to use a breast pump if you intend to breastfeed (approx. £15–150).
Financial support for formula feeding

<table>
<thead>
<tr>
<th>Name of support</th>
<th>What it offers</th>
<th>You are entitled to this if…</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sure-Start Maternity Grant</td>
<td>A one-off payment of £500</td>
<td>…you are expecting your first child, are expecting twins or triplets, or you or your partner are receiving certain benefits.</td>
</tr>
<tr>
<td>Healthy Start vouchers</td>
<td>You can use these for food, milk and baby formula at supermarkets, chemists and corner shops</td>
<td>…you are on Income Support, Jobseeker’s Allowance, receiving Child Tax Credit or are under 18 years old</td>
</tr>
<tr>
<td>Your GP</td>
<td>May be able to provide baby formula</td>
<td>This will depend on your local area. Ask your GP about eligibility.</td>
</tr>
<tr>
<td>Body and Soul</td>
<td>May be able to provide baby formula</td>
<td>…you are a member of Body and Soul.</td>
</tr>
<tr>
<td>The Food Chain</td>
<td>Short-term support with buying baby formula and groceries for people living with HIV in London</td>
<td>…you have been referred by your HIV clinic, midwife, peer supporter or HIV Support Organisation.</td>
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Child protection concerns

If you are taking your treatment, have an undetectable viral load and are adhering to the rules of ‘Safer Breastfeeding’ we will support you to breastfeed your child.

If you are not taking your HIV treatment every day and are still breastfeeding, the risk of passing HIV on 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 ever having to do this and want to work with you to care for your baby in the safest way. We have worked with many women with HIV who have had to make the decision about how to feed their new baby.

Some women choose to breastfeed 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 always clean’.
If you decide to formula feed, people may sometimes ask – or even pressure – you about why you are not breastfeeding.

**Peer supporter M.M. (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’.

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.

All new mothers need to make decisions about how they want to feed their baby. Having HIV just adds a few more things to think about.

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, doctors, paediatric nurses, Mentor Mothers and peer supporters. Take time to make your decision. Do not feel pressured by others.

If you feel you would like more support with making this decision you could consider talking to Mentor Mothers at Positively UK (Helen on 020 7713 0444 or email hrogers@positivelyuk.org) who would be very happy to talk things through with you.

Please talk to staff at the clinic, we are all here for you and your new baby and will be happy to help you.

**Acknowledgement**

Adapted from the Imperial College Healthcare NHS Trust, Family Clinic Leaflet, produced by Nell Freeman-Romilly, Angelina Namiba, Moira Marks, Paula Seery and Hermione Lyall (family.clinic@nhs.net).