A guide to infant feeding for people living with HIV

Feeding your game.

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Canada's source for HIV and hepatitis C information

# **In This Booklet**

Why formula feeding is recommended in Canada for people living with HIV	2
Doesn't taking HIV treatment prevent passing HIV?	3
Why is this recommendation different from others I have seen?	3
Make an informed decision and get the support you need	4
Feeding your baby formula	5
Where to get formula	5
Breast care	5
Bonding with your baby	6
Social and cultural pressures to breastfeed	6
Feelings about not breastfeeding	7
Breastfeeding	8
HIV medication for you and your baby	9
Medical appointments for you and your baby	9
Breast care	10
Limiting how long you breastfeed for, and switching	
to formula before introducing solid foods	11
Legal considerations	12
Find out more	13

# So, you're about to have a baby — congratulations!

Having a baby is an exciting time. It can also be an overwhelming time as you prepare to welcome a new member into your family.

One of the things you will need to decide is how you will feed your baby. In Canada, it is recommended that people with HIV feed their babies formula rather than breastfeeding.\* This is because HIV can pass to a baby through breast milk. Formula gives babies all of the nutrients they need without any chance of passing HIV to the baby.

Though formula feeding is recommended, breastfeeding is an option that you can consider. If you are interested in breastfeeding, discuss this option with a trusted healthcare provider. If you breastfeed, you and your baby will need support from a healthcare team to do so as safely as possible.

This booklet will walk you through some of the things you should know about feeding your baby. Reading this booklet, along with talking to a healthcare provider, can help you to make an informed decision.

\*CATIE acknowledges the diversity of people living with HIV who may have babies, which includes trans and non-binary people. We use the term breastfeeding in this resource because it is the most commonly used term. Some people prefer genderneutral terms such as nursing, chestfeeding or body feeding.

# Why formula feeding is recommended in Canada for people living with HIV

Experts in Canada recommend formula feeding for people with HIV because HIV can pass to a baby through breastfeeding. Taking HIV treatment and maintaining an undetectable viral load greatly reduces the chance of passing HIV to a baby through breastfeeding. However, there is still a very low chance of passing HIV.

We know for sure that there is no risk of HIV being passed when a baby is formula-fed. We also know that formula gives babies all of the nutrients they need for healthy development.





#### Doesn't taking HIV treatment prevent passing HIV?

As a person living with HIV, you probably know that successful HIV treatment is good for your health and prevents passing HIV to your sex partners. It also helps to prevent passing HIV during pregnancy and delivery. It may be surprising to learn

that there is a very small chance of passing HIV through breastfeeding when you are on treatment and have an undetectable viral load.

We don't know exactly why this is. It probably has to do with the fact that breastmilk contains a lot of immune cells. HIV may be able to "hide" in these cells, even when the viral load is undetectable. Also, a newborn baby's digestive system is still developing, which might make it easier for HIV to pass into their body.

# Why is this recommendation different from others I have seen?

In Canada, for most people who do not have HIV, breastfeeding is recommended. This is because breastfeeding has some health benefits for the baby. However, for people with HIV, experts recommend formula feeding because it is the only way to be sure that HIV will not be passed to a baby.

In some other countries, it is recommended that people with HIV take HIV treatment and breastfeed their babies. This is the recommendation in countries where malnutrition and life-threatening infections are common and where formula may not be available. In these countries, the small chance of passing HIV to a baby is less important than the benefits of breastfeeding for the baby's health.

# Make an informed decision and get the support you need

As a person living with HIV, choosing how to feed your baby can be a difficult decision. You might have strong feelings about how you would like to feed your baby. Talk to your HIV care provider about your desires and feelings about feeding. Ask any questions that you have. You have a right to receive information about formula feeding and about breastfeeding, including the risks and benefits of both options.

Besides talking to your healthcare provider, you might also wish to get other supports such as from a peer worker or a social worker.

It can take time to make sure that you understand the information and to process your feelings as you decide how you will feed your baby. It is a good idea to start thinking about how you will feed your baby well before they are born.



# Feeding your baby formula

If you decide to feed your baby formula, here are some tips and things to consider.

#### Where to get formula

In many parts of Canada, there are programs for people with HIV to access free formula. To see if there is a program near you, visit **catie.ca/formula**. Some areas do not have a formula program specifically for people with HIV, but there may be other programs that can provide formula. If you



are unsure where you can get free formula, you can ask a healthcare provider or someone at an HIV organization in your area.



#### **Breast care**

If you do not breastfeed, your breasts will probably still produce milk after you give birth. Your breasts may swell, and you might feel pain in your breasts because you are not releasing the milk.

You should not pump your milk. This is because pumping will cause you to

produce more milk. Not pumping might be uncomfortable for a few days but there are things you can do to help with this discomfort. You can wear a supportive well-fitting bra, use a cold pack, or take a pain reliever such as ibuprofen.

There is a drug called cabergoline available to help stop your body from producing milk. Talk to a healthcare provider about whether this might be a good option for you.

#### Bonding with your baby

Some people worry that not breastfeeding will make it harder to bond with their baby. There are lots of ways to bond with your baby besides breastfeeding. Any interaction you have with your baby is an opportunity for bonding. Holding your baby close on your bare skin and making lots of eye contact is a great way to physically bond with your baby. You can do this while feeding your baby with a bottle. Talking to your baby, singing, reading, and playing are all great ways to bond.



#### Social and cultural pressures to breastfeed

People who decide to formula feed their babies often face a lot of social and cultural pressure to breastfeed. You may feel that people are judging you for your decision not to breastfeed. This pressure and judgment can be upsetting.

You should know that you are not alone. Many people in Canada feed their babies formula for lots of different reasons. Some people do not breastfeed because of a health condition that they have or a medication that they take. Others feed their babies formula because they are not able to breastfeed or for other personal reasons. You may be worried that people might figure out that you have HIV because you are formula feeding. If you do not want someone to know that you are living with HIV, you may want to provide another reason for why you are not breastfeeding. For example, you could say that your body does not produce enough milk or that your baby prefers bottle feeding.

#### Feelings about not breastfeeding

Some people who decide to formula feed instead of breastfeeding feel comfortable with their decision. For others it can bring up feelings of sadness, shame, or loss. Some people may worry about whether they are doing the right thing for their baby. These feelings are normal. If you are struggling with your feelings, it might be helpful to talk to other parents who are living with HIV or to get support from a mental health care provider.



## Breastfeeding

If you decide to breastfeed your baby, it is important to work with a knowledgeable healthcare team who can monitor your health and support you and your baby. Canadian guidelines recommend several things that can help prevent passing HIV to your baby while breastfeeding. Read on to learn about these recommendations.



#### HIV medication for you and your baby

It is very important to keep taking your HIV medication consistently when your baby is born. Taking your medication is good for your health. It is also the most important thing you can do to reduce the chance of HIV passing to your baby when you breastfeed.



When you have a new baby, you may be sleep deprived and you may lose track of time. This can make it difficult to take medication on a regular schedule. It can be helpful to set an alarm as a reminder. You can also use a pill organizer or ask your pharmacist to package your medication in blister packs, so that you can check if you have taken your medication each day. If you are having trouble taking your medication, talk to a healthcare provider.

To further reduce the chance of passing HIV, it is recommended that your baby be given HIV medications as well. These medications are given to your baby throughout the time that you are breastfeeding, and for another month afterwards. They are safe for babies to take.

#### Medical appointments for you and your baby

During the time that your baby is breastfeeding it is recommended that you have an appointment once every month. At these appointments, you will have a viral load test to make sure that your HIV treatment is working. Your baby will also be tested for HIV frequently while you are breastfeeding to make sure that they are still HIV negative. They will also be monitored for drug side effects. These appointments are an opportunity for a healthcare provider to check how you are doing and for you to ask any questions that you have.

#### **Breast care**

Keeping your breasts healthy will be more comfortable for you and may help reduce the chance of passing HIV to your baby. If you experience cracked nipples or mastitis (inflammation in your breast, sometimes caused by an infection), this might increase the chance of HIV passing to your baby.

It can be helpful to get support from a lactation consultant. Lactation consultants are healthcare providers who specialize in breastfeeding. They can help to show you how to get your baby to latch properly, which can reduce the chance of your nipples cracking or bleeding.

If one of your nipples becomes cracked or you think you might have mastitis, it is recommended that you stop breastfeeding from that breast until it is resolved. If you think you might have mastitis, talk to a healthcare provider right away to get treatment for the infection. They will give you advice about what to do until the issue is resolved.





#### Limiting how long you breastfeed for, and switching to formula before introducing solid foods

You can reduce the chance of passing HIV by breastfeeding for a shorter time period. Breastfeeding for only a few weeks or months has a lower risk of passing HIV than breastfeeding for six months or longer.

There may be a higher chance of passing HIV if you start feeding your baby solid foods in addition to breastmilk. This is sometimes called mixed feeding. Because of this, some experts recommend that you consider switching to formula before introducing solid foods. Solid foods are normally introduced when a baby is four to six months old. Talk to a healthcare provider about your plans for when you will stop breastfeeding. They can give you advice on how to wean your baby off of breastmilk.

#### Legal considerations

Guidelines for healthcare providers on HIV and infant feeding recommend that a person with HIV should not be reported to child protective services for breastfeeding, if there is no significant risk of passing HIV to the baby. Following your healthcare provider's advice about how to breastfeed as safely as possible is important to help prevent any potential legal consequences of breastfeeding.



If a healthcare provider feels that there is a significant risk of passing HIV to a baby, they might contact child protective services. For example, this might happen if you breastfeed while you have a detectable viral load, if you regularly miss medical appointments while breastfeeding, or if you breastfeed without the support of a healthcare provider.

Some healthcare providers are not familiar with the recommendations about breastfeeding for people living with HIV. It can be helpful for you to print out a copy of the Canadian guidelines when you are going to see a new healthcare provider. You can find a copy of these guidelines at catie.ca/infant-feeding.

It can also be helpful to sign an agreement with your HIV doctor, so that you have a document that shows that you are breastfeeding with the knowledge and support of your doctor.

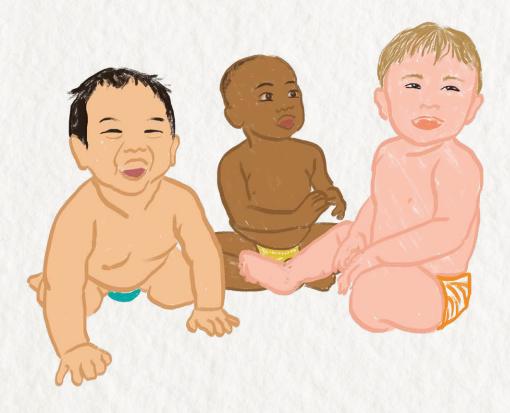
If you are contacted by police or child protective services related to your choice to breastfeed, you can get support. Visit **whereto.catie.ca** to find HIV organizations and legal services near you.

# Find out more

We hope the information in this booklet has been helpful to you. Make sure to get in touch with a healthcare provider about your plans and to get the support you need.

To find services near you, visit whereto.catie.ca.

For information about HIV, visit catie.ca.





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