Breastfeeding
for women living with HIV in Australia

Access and download a PDF copy of this community resource

Living WELL
WOMEN WITH HIV

napwha national association of people with HIV australia

PositiveWomen
Support and advocacy for women living with HIV

Acknowledgements:

This resource is adapted from information in the BHIVA (British HIV Association) HIV and breastfeeding your baby and General Information on infant feeding for women living with HIV (2018). The guidance is also to be used in conjunction with the clinical guidance resource produced by ASHM (Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine) – *The Optimal Scenario & Context of Care. ASHM Guidance for Healthcare Providers regarding Infant Feeding Options for People Living with HIV with highlights from Breastfeeding and Women Living with HIV in Australia* (2021).

This resource is an initiative that forms part of Living Well: Women with HIV – an on-going website collaboration between NAPWHA and AFAO since 2016.

This initiative was also developed and produced under the **NAPWHA HIV Health Literacy Framework (HLF) project** – a framework approach which uses community-led participatory action research, led by HIV community advocates with networks of HIV peers, to inform health promotion. This resource was produced in shared collaboration between NAPWHA and Positive Women Victoria.

The NAPWHA HLF project (2019-2021) was made possible through the funding support of ViiV Healthcare Australia.

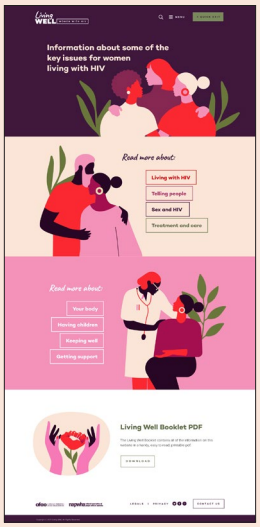
Illustrations – www.carolina-relander.com
Graphic Design – www.danielcordnerdesign.com

Editorial team:

Heather Ellis Positive Women Victoria
Dr Kirsty Machon Positive Women Victoria
Adrian Ogier NAPWHA
Saysana Sirimanotham NAPWHA

With thanks to:

Brent Allan ICASO
Kate Bath ASHM
Sarah Feagan Community Advocate
Femfatales National Network of Women Living with HIV
Lara Kruizinga Community Advocate
Melania Mugamu QPP
Abbie Opuama QPP
Daniel Reeders NAPWHA
Emma Sheldon Collins Community Advocate
Positive Women Victoria focus group participants



Note for trans parents living with HIV

This resource has been developed for women who are gestational parents. It is an initiative of NAPWHA's Health Literacy Framework project, which used a community development approach to engage with and amplify the experiences of a network of positive women. The epidemiology of HIV in Australia means that women living with HIV who are cisgender and heterosexual are a small minority of HIV cases. To reflect the lived experience of our participants we use the terms women and mother throughout the document.

NAPWHA recognises that people who feed infants with human milk are diverse in terms of gender and sexuality. This includes trans men and transmasculine and nonbinary people for whom the language in this document will not be appropriate. NAPWHA has produced a version of this resource that uses gender-neutral language and includes information on chestfeeding and supplemental feeding.

The resource is available from the NAPWHA website https://napwha.org.au/resources/

Contents

2 Who this resource is for

3 Whether or not to breastfeed

4 Preparing to make a choice

4 Your healthcare team and their role

10 Social and emotional issues

12 Breastfeeding and your HIV medications

13 Dos and Don'ts

15 U=U and breastfeeding

15 Scientific studies

17 Medical appointments for you and your baby

18 Breastfeeding problems and breast infections

19 How to feed your baby on stored expressed breastmilk or formula

20 Your right to make the decision without pressure

20 Your partnership with your HIV clinic healthcare team

20 Support from partners, friends, or family

20 Your partnership with your doctor (GP) and a lactation consultant

22 Talking points: What you can say

24 What if I am unhappy with how I am treated?

25 What you need to know if you are considering formula feeding

26 Other options for infant feeding

26 Where to find further help and support

27 Pregnancy and breastfeeding for women living with HIV in Australia Supplementary Referral Flowchart

Who this resource is for

If you are living with HIV and you are pregnant or thinking about becoming pregnant, you may be thinking about breastfeeding your baby, and whether it is safe or advisable.

The information in this resource is provided for women who are living with HIV and want to understand the issues around breastfeeding or formula feeding.

We hope after reading this information, you will feel encouraged by the news that although medical and health experts agree that formula feeding is still the safest option, breastfeeding is increasingly being recognised as an option that may be open to some women living with HIV.

We encourage you to use this information to start a discussion with your doctor or health care team.

We recognise that for any individual woman living with HIV, there are many things to consider when deciding what is best for feeding your new baby. The information in this factsheet may be of use, but the decision will not be the same for all women. We encourage women living with HIV to:

- **Take your time with this decision and consider including this for discussion early in your pregnancy or family planning process.**
- **Talk to your HIV peer support worker, who is there to listen to you, guide you through the information, and support you through this process.**

Whether or not to breastfeed

Many new mothers wish to breastfeed their new baby for reasons including bonding and the proven nutritional and immunological benefits of breastmilk. Women living with HIV are no different, but the decision whether to breastfeed can be more complicated because of the potential for HIV to be transmitted to your baby through breastmilk.

HIV treatment uses a combination of antiretroviral medication to reduce the amount of HIV in your blood and body tissues. We use blood tests to monitor your viral load, which commonly refers to the amount of HIV in a sample of blood. We say HIV treatment is *effective* when viral load is lower than able to be detected in standard blood test.

The new science of HIV transmission shows that effective HIV treatment eliminates the risk of HIV transmission during sexual intercourse. But what about breast feeding?

Taking HIV medication and having an undetectable viral load can also reduce the risk of HIV transmission from a mother to a baby during breastfeeding to extremely low levels. However, from what we know from studies, it does not reduce the risk completely to a zero risk. Part of the reason may be that HIV can be present in breast milk even when the viral load in blood is so low that modern tests cannot pick it up. This is known as 'undetectable.'

Formula feeding using infant formula is recommended as the safest way to feed your baby in settings such as Australia, where clean water is readily available to mix the formula into liquid. However, there is a growing recognition, both in Australia and around the world, that when a mother is taking HIV medications, has an undetectable viral load, and the right care and support from a healthcare team breastfeeding may be a reasonable option.

Preparing to make a choice

Deciding whether to breastfeed or formula feed is a big decision. Make sure to take care of yourself as you prepare to make the best possible decision for you and your baby. You - and your partner if you choose - should decide how your baby will be fed. But you do not have to make this decision alone.

It is important to find a supportive healthcare team, which will include your HIV specialist doctor. This team should be knowledgeable and experienced in management of women living with HIV who choose to breastfeed. This support network may also include a lactation consultant – a health professional specialising in breastfeeding. It is also a good idea to connect with HIV-positive peers and other women living with HIV who have breastfed. They will be good sources of information and support.

If you do choose to breastfeed, it is vital for you and your baby that you take your HIV medications regularly and on time, and that you attend all HIV clinic appointments and viral load tests.

Understanding the risk

Recent studies show that the risk of transmitting HIV through breastfeeding is extremely low when:

- you are taking your HIV medication on time and as prescribed;
- your viral load has been undetectable during your pregnancy and remains undetectable while you are breastfeeding;
- you are receiving regular medical care; and
- you breastfeed for a short time, and for no more than six months.

A trial called the PROMISE study included over 2,400 mothers who were living with HIV and taking antiretroviral treatment. Among participants, 64% had viral loads under 400. HIV transmission risk to babies from breastfeeding was 3 in 1000 at six months.[1] However, if women breastfed longer than six months, that risk increased to 6-7 in 1000 babies. The risk of HIV transmission to babies was also increased in this trial where mothers experienced an increase in their viral load or a decrease in their CD4 T-cell count during the time when they were breastfeeding.[2] This shows why it is important to keep appointments with your healthcare team and have any blood tests recommended by your doctor or health care team, so that any changes or concerns can be quickly identified.

An important discussion paper from Switzerland in 2018 suggested that if a mother is adherent to treatment, has undetectable viral load, and is receiving good care, it may be reasonable to consider breastfeeding as an option, especially given the known health and social benefits.[3]

There are many women living with HIV in Australia and overseas who have safely breastfed their babies. In countries and settings where clean water is not reliably available for mixing with baby formula, breastfeeding along with HIV medications is the recommendation by the World Health Organisation (WHO).[4] This is because the risks of a baby becoming dangerously unwell from water borne illnesses is high, and this is considered to outweigh the risk of HIV transmission from breastfeeding.

[1] Flynn PM, et al *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.* J Acquir Immune Defic Syndr. 2018 Apr 1;77(4):383-392. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5825265/

[2] Flynn et. al. *Association of Maternal Viral Load and CD4 Count with Perinatal HIV-1 Transmission Risk during Breastfeeding in the PROMISE Postpartum Component.* JAIDS Journal of Acquired Immune Deficiency Syndromes Publish Ahead of Print DOI: 10.1097/QAI.0000000000002744

[3] Kahlert, C et al. (2018). *Is breastfeeding an equipoise option in effectively treated HIV-infected mothers in a high-income setting?* Swiss Medical Weekly, 148: w14648. https://doi.org/10.4414/smw.2018.14648

[4] World Health Organization, United Nations Children's Fund. *Guideline: updates on HIV and infant feeding: the duration of breastfeeding, and support from health services to improve feeding practices among mothers living with HIV.* Geneva: World Health Organization; 2016. https://www.ncbi.nlm.nih.gov/books/NBK379872/

Your Multidisciplinary health-care team and their role

For more detail of what to expect from members of your healthcare team, a referral flowchart – Pregnancy and breastfeeding for women living with HIV in Australia – is also included as a supplement in this resource.

HIV specialist doctor	Once your pregnancy is confirmed, your HIV specialist doctor who prescribes your HIV medications, refers you to either (or both) an **Infectious Diseases specialist doctor** and/or an **Obstetrician**. This will depend on the Australian State or Territory where you live. If you or your baby are unwell, or you develop any breast or nipple infection, it is important to seek advice from your **General Practitioner (GP)** as soon as you suspect a breast infection. In this period, your HIV specialist doctor will coordinate the regular blood tests for you and your baby. These blood tests monitor your viral load and check that your baby has not contracted HIV from your breastmilk.
Infectious Diseases specialist doctor	An **Infectious Diseases specialist doctor** provides ongoing care and management of HIV and any other infections during pregnancy. This includes providing you with education about methods of reducing HIV transmission to your baby. They will ensure that you are linked to an **HIV multidisciplinary team** and **paediatric infectious diseases team**. Note: A Sexual Health or HIV s100 prescribing doctor who specialises in the care of women living with HIV and pregnancy may fulfill the same role as an Infectious Diseases specialist doctor.
Obstetrician	Your **Obstetrician** arranges your routine blood tests and monitors your blood results specific to pregnancy. They arrange ultrasounds to check on your baby's growth and position baby's birth. They also have specialist skills to manage complex or high-risk pregnancies and births. They manage and discuss your labour as either a natural birth or a caesarean.

Multidisciplinary team (MDT) and pediatric infectious diseases team	Pregnant women with HIV will be linked into a **multidisciplinary team (MDT)** made up of many different people. These may include: **Specialist HIV nurses** and **nurse practitioners** who are linked in with your MDT service and may provide education, counselling about HIV and its management, and talk to you about feeding options for infants. **Specialist midwives** who are involved in your 'obstetric care', a phase relating to childbirth and the processes associated with it. **Lactation consultants** who specialise in helping mothers to breastfeed. They provide information and support in showing you the correct techniques that will help you avoid breast infections and other problems. **Social workers** who can provide social support should you need it. **Pediatric infectious diseases team** who can prescribe the antiretrovirals for your baby and manage your baby's regular blood tests after birth.
HIV peer support worker / HIV peer navigator	An **HIV peer support worker** or **HIV peer support navigator** can help support you in communicating with your **multidisciplinary team**. They can also provide information on where you can find HIV specialist healthcare professionals. In some cases, they may be able to connect you with other women living with HIV who are/have breastfed and may be able to provide social support. Contact **Positive Women Victoria** or your state-based PLHIV organisation. These contacts can also be found on the NAPWHA website – https://napwha.org.au/hiv-peer-support/

Make your decision only after a discussion with your HIV healthcare team (and your partner if you choose). Make the decision together after considering all the risks and benefits of breastfeeding.

This discussion needs to take place early in your pregnancy – within your first trimester – so that information and support can be arranged and provided for you.

Organisations representing people living with HIV in Australia, including Positive Women Victoria and NAPWHA (National Association of People with HIV Australia) hold the position that:

1.

Women living with HIV who are taking HIV medications (combination antiretroviral treatment), who have a suppressed HIV viral load (<50 copies) throughout pregnancy, and are under the care of a supportive, knowledgeable health practitioner, can consider the option of breastfeeding.

2.

Breastfeeding is safest when women are supported by a strong healthcare team and have received clear information and counselling about strategies to prevent transmission of HIV through breastmilk in a way that is understandable to and culturally appropriate for the woman.

3.

Women living with HIV should be supported to make the decision about how to feed their baby without coercion or judgement, or legal interventions.

Before effective HIV treatments became widely available, there was a significant risk of HIV transmission to babies through breastfeeding. That is why formula feeding has usually been recommended for women in settings where clean water is available to safely mix the formula.

Although HIV treatment has dramatically reduced the risk of HIV transmission in breast milk, it has not been entirely eliminated. Among the reasons:

- HIV can be present in breastmilk.
- HIV can be present in the immune cells in breastmilk.
- Common problems when breastfeeding (such as infection of the breast, or mastitis; or cracked or bleeding nipples) can increase the risk of HIV being transmitted to a baby.
- If a baby has a 'gastro' problem such as diarrhoea while breastfeeding the risk may increase.
- If HIV viral load is not completely suppressed, this can increase the risk of transmission.
- The amount of HIV in your blood (your viral load) is not always the same as that in your breastmilk. The level of HIV can be higher in breastmilk even when your viral load in blood tests is undetectable.

The risk can be reduced but not eliminated by:

- Taking HIV medications and ensuring you have an undetectable viral load in your blood.
- Looking after your breast health and receiving advice or support about this from your GP, specialist, or a health care worker such as a nurse or lactation consultant.
- Making sure that if you do have cracked, bleeding or irritated breasts/nipples, or if you or your baby become unwell, that you stop breastfeeding straight away and see your doctor.

Social and emotional issues

Breastfeeding can be an emotional issue. Many women who have been living with HIV for some time have experienced having children during a period of great uncertainty about HIV treatment. At that time, many of these women were told they could not breastfeed.

An issue for some women born overseas may be the different advice given in Australia (where women are usually still advised not to breastfeed) to that given in their own culture or country of origin.

The World Health Organization recommends exclusive breastfeeding for babies born to mothers with HIV for the first six months of life. This advice was developed for settings where there is unreliable access to clean water to mix with baby formula, as well as ways to sterilise bottles and teats. Baby feeding formulas can also be expensive or difficult to access. Unclean water can put babies at increased risk of diarrhoea and other dangerous illnesses. However, in countries like Australia, where clean water is reliably available, the advice is different.

You may feel you are receiving conflicting advice or even pressure from healthcare practitioners, friends and family as to whether or not to breastfeed. Some may be supportive while others may suggest you should not breastfeed.

Women who come from countries where HIV rates among women are higher than in Australia may be concerned that not breastfeeding is a sign they are living with HIV.

Other women may feel considerable pressure not to breastfeed from doctors, nurses, or other health practitioners. Some may even have been told they may be referred to social services, such as child protection services, if they breastfeed.

You should never be asked to make this decision under any kind of pressure. You can seek the support of a community services for people living with HIV to discuss this in-confidence if you need support or feel pressure to make decisions you do not feel comfortable with.

The risk of HIV transmission to your baby, even when your viral load remains undetectable (<50 copies), increases the longer you breastfeed. The recommendation is that, if you breastfeed, you breastfeed for no longer than six months.

Breastfeeding and your HIV medications

Excitement and happiness are part of having a new baby. But interrupted sleep, anxiety, forgetfulness and even depression can all be a part of new motherhood, too. Self-care is important. Make sure you have practices in place so you always remember to take your HIV medications at this time. If you have other health conditions, you should also make sure you are looking after yourself and following all recommendations.

If you experience issues such as diarrhoea or illness, talk to your HIV doctor immediately, as this may result in poor absorption of your HIV medications which can cause your viral load to rebound.

There is a lot of experience around the world of women living with HIV giving birth and breastfeeding babies who grow up healthy and happy, without HIV or the effects of HIV medications. However, more research on the presence of long-term effects of HIV medications that the baby absorbs through breastmilk would be welcome.

Dos and Don'ts to reduce the risk of HIV transmission from breastfeeding

DO

Do consult with a multidisciplinary healthcare team early in your pregnancy – within the first trimester.

Do take your HIV medications every day and on time.

Do attend all your HIV clinic appointments for you and your baby. It's important not to miss any appointments.

Do take care of your breasts. Get advice and support on how to look after your breasts from your doctor, nurse, or lactation expert (someone with expert knowledge about breastfeeding).

Do breastfeed for the shortest time possible and for no longer than six months. Studies suggest the risk of transmission through breastfeeding begins to increase after six months.

DON'T

Don't breastfeed if your viral load becomes detectable or if you are having trouble taking your HIV medications. Switch to feeding your baby with infant formula and don't return to breastfeeding.

Don't breastfeed your baby if your baby has diarrhoea or is vomiting. Switch to formula feeding and contact your doctor to be guided. Do not return to breastfeeding without expert advice from your healthcare team.

Don't breastfeed if you have diarrhoea and/or are vomiting. If you already have stored expressed breastmilk, talk to your doctor about whether if it is safe to use this. Otherwise, switch to formula feeding and don't return to breastfeeding.

Don't breastfeed if you develop mastitis (an infection in the breast caused by a blocked milk duct). It is recommended to start formula feeding, and not return to breastfeeding. Consult your expert healthcare team.

Don't breastfeed if you have cracked or bleeding nipples.

Don't 'mix feed' your baby on both breastmilk and formula. If you switch to formula feeding, do not return to breastfeeding. Research shows bottle and breastfeeding (sometimes called 'mixed feeding') may increase the risk of HIV transmission.

I Am...	Is breastfeeding potentially an option to discuss with doctor?	Things to consider
• ... taking my HIV medications as prescribed. • ... undetectable, with a viral load of under 50 copies prior to and throughout my pregnancy. • ... willing and able to attend all medical and follow-up appointments for testing and monitoring. • ... generally well and healthy.	• Yes	• It is important to understand how to care for your breasts. • You and your baby will be recommended to undergo regular HIV testing. • Always seek advice if concerned about your breast symptoms, or signs you or your baby may be unwell.
• ... taking HIV medications, but I have not been able to sustain undetectable viral load for over six months. • ... likely to find it difficult to attend medical follow-up and all my appointments. • ... concerned about my baby being tested for HIV as this might upset me. • ... living with other health conditions that also require support.	• Formula feeding will likely be recommended	
• ... currently not taking HIV treatment. • ... unaware of my current viral load.	• Breastfeeding would not be a safe option. Formula feeding is the safe option.	• HIV treatment during pregnancy protects both you and your baby.
• ... currently not taking HIV treatment. • ... aware that my viral load is very high.	• Breastfeeding would not be a safe option. Formula feeding is the safe option.	

U=U and breastfeeding

If HIV is at levels too low to be detected in your blood, this is known as being 'undetectable'. HIV treatment helps most people achieve this outcome. When viral load is under 200 copies per millilitre of blood, it means that HIV cannot be transmitted to sexual partners, even if you do not use condoms during sex. This is widely described as "undetectable equals untransmittable" (U=U), even though the testing technology used in Australia can detect much lower amounts of virus.

The U=U message should not be applied in pregnancy however, given that viral load is not tested in breast milk as a routine. A breastfed infant receives a very large and ongoing 'dose' of human milk, compared to the fleeting exposure to body fluids that can occur during sex. This creates a much greater opportunity for a viral particle to invade the baby's developing immune system and for HIV infection to take hold. Effective HIV treatment reduces the risk considerably, but it cannot be described as untransmittable.

Find out more about U=U via the Women Living Well website:

Read more

Scientific studies

Since 1991, there have been around 26 studies researching HIV transmission to babies through pregnancy and breastfeeding. These studies have included nearly 20,000 mothers with HIV and their babies. Not all mothers in these studies had sustained durable viral suppression while taking HIV medications.

There are no clinical trials looking at HIV transmission rates through breastfeeding in Australia. It would be hard to do this research in Australia as the numbers of women living with HIV and having babies at any given time is very small.

In developing countries such those in Africa and Asia, where all these studies have been conducted, the risk of HIV transmission via breastmilk when women are taking HIV medications is as low as 0.3% (PROMISE study) when babies were breastfed for six months. The figure increased to 0.6% at 12 months of breastfeeding.

PROMISE study

Promoting Maternal and Infant Survival Everywhere (PROMISE) is an ongoing study in resource limited settings. The most recent study was run between June 2011 and October 2014 in South Africa, Malawi, Tanzania, Uganda, Zambia, Zimbabwe and India, with 2,431 pairs of mothers and babies. All mothers received antiretroviral treatment during pregnancy and while breastfeeding. In the mothers who received triple therapy the study found the rate of HIV transmission from breastmilk was very low — 0.3 percent at six months of age and 0.6 percent at one year of age. The study found the longer the mother breastfeeds, the greater the risk for HIV transmission to her baby. Researchers also concluded transmission of HIV through breastmilk in high-income settings (like Australia) may be similar, and that antiretroviral treatment adherence where the mother has an undetectable viral load may virtually eliminate transmission risk, much as it has from pregnancy and delivery.

Read more about the PROMISE study:

Read more

No HIV Transmission from Virally Suppressed Mothers During Breastfeeding in Rural Tanzania

Run from 2013 to 2016, this study included 214 mothers taking antiretroviral HIV medications. The researchers concluded that no baby contracted HIV from breastmilk when the mother was taking HIV medications and had sustained durable viral suppression.

Read the report

Read more

DolPHIN 2 study

From 2018 to 2019, this study followed 268 pregnant women with HIV and their babies after birth and while breastfeeding, in Uganda and South Africa. Antiretroviral treatment (either dolutegravir or efavirenz) was prescribed late in pregnancy. Researchers found both treatments were safe and effective for pregnant women with HIV and their babies, and mother-to-child transmission was uncommon during pregnancy and breastfeeding. However, one baby contracted HIV during breastfeeding where the mother was taking efavirenz and three babies contracted HIV in-utero where the mother was taking dolutegravir. Researchers said this emphasised the importance of treatment early in pregnancy.

Read more about the **DolPHIN 2 study**

Read more

Medical appointments for you and your baby

If you decide to breastfeed, you and your baby will need to attend regular medical appointments with your HIV healthcare team. You and your baby will be required to have regular blood tests to check that your viral load remains undetectable and that your baby remains HIV negative. Your baby will also receive an HIV test within 48 hours after birth, at two weeks of age and then at four-week intervals until breastfeeding has stopped. If a test finds your viral load is no longer undetectable, you must stop breastfeeding and start formula feeding. You cannot return to breastfeeding in absence of expert advice from your healthcare team. Your baby will also continue having immunisations as per the Australian immunisation schedule.

After you have stopped breastfeeding, you and/or your baby will have several more blood tests. This is to test that the baby has cleared HIV antibodies they received from your breastmilk.

The number of blood tests your baby will require may be a consideration when deciding whether to breastfeed or not.

HIV blood testing schedule for you and your baby

PEP (post-exposure prophylaxis) for your baby for four weeks

From birth, your baby will be treated with HIV medications for a period of four weeks to help ensure he or she remains HIV negative. This treatment is called post-exposure prophylaxis (commonly known as PEP) and is given to all babies born to mothers with HIV regardless of whether they breastfeed or not. Even though your viral load is undetectable, PEP is an added safety measure to protect your baby from HIV over the first four weeks of their life. Your baby may experience adverse effects. To ensure a growing baby is not exposed to HIV medications longer than is absolutely needed, PEP is generally only given for four weeks.

Breastfeeding problems and breast infections

Breastfeeding does not come easily for every mother. Your baby may not latch on to your breast easily. Sometimes, mothers may produce only small amounts of milk, which can be upsetting or distressing for both of you. Others may have painful or enlarged breasts due to milk production. It is important to have the support of a qualified and non-judgmental lactation consultant who is knowledgeable about breastfeeding issues. Lactation consultants might be excellent at what they do, but may not know a great deal about HIV, so it's important that all your healthcare providers are working as a team.

Cracked nipples, infections, and mastitis

Cracked or bleeding nipples can be caused by infections or irritation from breastfeeding. Mastitis is one of the most common problems experienced by breastfeeding women and affects about one in six women in Australia. Breast infections, or mastitis caused by blocked milk ducts, can increase HIV viral load in breastmilk of mothers who do not have an undetectable viral load. However, this has not been studied in mothers taking triple combination HIV medications who have a sustained undetectable viral load. Therefore, the current and safest recommendation if you develop mastitis is to stop breastfeeding and start formula feeding and do not return to breastfeeding after the infection has healed. Your HIV healthcare team can help support you or connect you to a lactation consultant to help you understand how to take care of your breasts and nipples.

If you or your baby have an upset tummy

If you and/or your baby have an upset tummy with diarrhoea and/or vomiting, this increases the risk of your baby contracting HIV. The HIV medications you take may not be absorbed causing the virus to become active. An irritated baby's tummy means it is easier for HIV to cross into their bloodstream. If your baby has an upset tummy, you will have to stop breastfeeding and start formula feeding. You cannot go back to breastfeeding after your baby is well again. If you have an upset stomach, you can use stored expressed breastmilk from two days before you were unwell and return to breastfeeding when you are well again. But remember, if you begin formula feeding, you cannot return to breastfeeding in the absence of expert advice.

Mastitis (infection in the milk ducts of the breast tissue which can occur during breastfeeding) has been shown to increase HIV viral load in breastmilk in mothers who do not have an undetectable viral load. However, this has not been studied in mothers taking triple combination HIV medications who have a sustained undetectable viral load.

How to feed your baby on stored expressed breastmilk or formula

Be prepared with formula and stored expressed breastmilk

Before the birth of your baby, you will need to purchase formula, bottles, teats, sterilised equipment, and a breast pump. While your breasts and tummy are healthy, you should express your breastmilk and then freeze it in sterilised containers. Write the date and volume on the container before you freeze it.

Expressing breastmilk

When your breasts have an infection and/or your nipples are cracked or bleeding or you and your baby have an upset tummy, you will need to express milk using a breast pump and throw this milk away as it cannot be fed to your baby later. Try not to empty your breasts completely as this will trigger an increase in supply.

How to stop breastfeeding

If you must stop breastfeeding completely and feed your baby on formula, your doctor and/or lactation consultant can advise you on how to safely dry up your breastmilk.

If you develop a breast infection close to when your baby is six months old, stop breastfeeding and seek advice from your healthcare team.

Information on safely drying up your breastmilk can be found at the **Australian Breastfeeding Association** website:

Read more

Weaning your baby off breastmilk

At around the age of six months, your baby is ready to start eating solid food.

In the UK, the recommendation for a woman with HIV to wean her baby off breastmilk, is change to formula milk only, and then introduce solid food gradually over a few weeks.

Consult your HIV healthcare team well in advance to plan your strategy for transitioning your baby from breastmilk to solid food.

At six months, your baby is ready for new foods, textures and they need more nutrients from the five food groups than can be provided by breastmilk or formula alone. The best way to feed your baby solid food is to puree the meals you prepare for your family. Your baby will then receive a balanced, varied diet.

Information on introducing foods to babies can be found at the **Australian Breastfeeding Association** website:

Read more

Your right to make the decision without pressure

As a woman living with HIV, you should be supported to make an informed decision about feeding your baby. This decision should not be made under pressure from anyone else.

Health practitioners may hold different views about breastfeeding when you have HIV. In some cases it will not be safe to breastfeed. If that is the advice given by your clinician, it is important to listen and take that advice very seriously. However, your health practitioner should not close the discussion down and should be willing to help you understand all the issues so you can both be confident in your decision. If you are not confident in the advice you receive, you may consider seeing a different practitioner for a second opinion.

Your HIV peer support organisation can be a place to turn if you want support in opening this discussion. NAPWHA and Positive Women Victoria stand by the principle of informed choice. This should never be resolved by intervention from other services or be treated as a child protection issue.

Your partnership with your HIV clinic healthcare team

If you wish to breastfeed, your HIV specialist doctor connected to your HIV clinic will be able to answer your questions and help clarify any concerns. They may want to seek guidance from ASHM (the Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine). ASHM has developed guidance for clinicians on breastfeeding for women living with HIV.

You may also want to talk with an HIV peer support worker or an HIV peer navigator from your Australian state-based PLHIV organisation, who can help you with information and referrals. You can discuss with them where to find health practitioners who are experienced in managing HIV throughout pregnancy and early motherhood.

Support from partners, friends, or family

As with many health care decisions, it can be helpful to discuss your issues and concerns with others. If you have a partner (the parent of your child, or another intimate partner) who is supporting you throughout this process, you may wish to discuss breastfeeding with that person, and talk about the risks and benefits together. You may also have a family member or close friend you trust. Some women find it helpful to talk to other women living with HIV who have been through the experience of motherhood or are considering it.

Your partnership with your doctor (GP) and a lactation consultant

As breastfeeding is not always straight forward, it is recommended that you also have a doctor (General Practitioner) and a certified lactation consultant. Both will be bound by the same confidentiality requirements as any other healthcare provider.

We recommend that you inform your doctor and lactation consultant that you are living with HIV because proper breastfeeding techniques can help avoid breastfeeding problems which can lead to breast infections. It is important you tell your lactation consultant that you have HIV because management is different, e.g. removal of milk and even continuing to breastfeed is the mainstay of mastitis treatment for women without HIV. Positive Women Victoria and other HIV sector organisations are working together to educate lactation consultants about HIV and breastfeeding.

You can advise your doctor and lactation consultant where they can learn more about HIV and breastfeeding. You may decide to provide them with the contact details of your HIV specialist doctor at your HIV clinic. A peer support worker who is also living with HIV may also be a source of information.

Talking points: What you can say to your doctor and lactation consultant

This list of 'talking points' can help you to build a partnership with your doctor and lactation consultant, particularly if they are not familiar with the latest HIV and breastfeeding guidelines and research on HIV transmission and breastfeeding.

1.

The risk of HIV transmission to my baby from breastfeeding is almost zero when my viral load is undetectable. My viral load has been undetectable for ___ (*you can advise this if you choose*). This is because I take my HIV medications every day and on time. I know that if my viral load becomes detectable, I will stop breastfeeding and start formula feeding and I will not go back to breastfeeding.

2.

Research shows that the risk of HIV transmission when the mother is taking HIV medications and has an undetectable viral load and only breastfeeds for six months is as low as 3 in 1000. However, there have been no studies yet in countries like Australia.

3.

The World Health Organization recommends all mothers with HIV should be supported in their choice to breastfeed. Due to the lack of access to clean water and the cost of formula, mothers with HIV in low- and middle-income countries are recommended to breastfeed for the first six months of life.

4.

Like any new mother, I feel strongly that it is important to breastfeed my baby. I want my baby to have the nutritional and immune-boosting benefits of breastmilk. The benefits of breastfeeding are clinically proven including for the baby's health and the wellbeing of the mother and baby through bonding. I know that the risk is almost zero when I do all the right things to minimise this risk.

5.

I have spoken to my HIV clinic and they fully support me with my decision to breastfeed. They are very experienced and have explained that I will need to attend regular appointments to have regular blood tests for me and my baby. I understand how important this is, and I am very willing to follow this process.

6.

I understand all the transmission risks from breastfeeding. To keep the risk of HIV transmission to nearly zero, there is to be no mixed feeding while I am breastfeeding during the first six months. If I use formula for any reason, I cannot go back to breastfeeding. I will have bottles, teats, and sterilising equipment on hand just in case.

7.
I understand that if my baby has an upset tummy, I must start formula feeding. I cannot use any stored breastmilk even from when my baby was well, and I cannot go back to breastfeeding.

8.
I understand that I must only breastfeed for the shortest time possible and no longer than six months. When my baby is six months old, the safest way to feed my weaning baby is to use only formula milk and no breastmilk. This is the recommendation from the British HIV Association who say that until scientists know more, this is the safest way to feed a weaning baby.

9.
You may have heard about the term U=U (Undetectable equals Untransmittable). U=U only applies to sex and does not yet apply to breastfeeding because now scientists are still gathering the data needed to completely rule-out the risk of transmission via breastfeeding for a woman with an undetectable viral load.

10.
If I do not breastfeed, I am concerned that my family will find out I have HIV because they will continually question me as to why I am feeding my baby on formula milk. If they find out I have HIV this may impact on both my baby's and my emotional wellbeing into the future.

11.
My HIV healthcare team have explained to me that I will not be reported to child protection services and there is no risk of my baby being taken away from me if I am attending all my appointments and follow the HIV and breastfeeding guidelines. If I am reported for any reason, my HIV clinic and my HIV organisation will support me.

12.
As a woman, it is my right to seek information and make an informed choice about feeding my baby regardless of my HIV status. This includes consideration of breastfeeding. With an undetectable viral load, I know the risk of HIV transmission to my baby is almost zero when I follow the recommended guidelines.

13.
In this rapidly changing environment where the HIV transmission risk from breastfeeding is almost zero due to the effectiveness of triple combination HIV medications, more and more women living with HIV are choosing to breastfeed. The UK, Switzerland, Canada, the United States and Australia have now all developed or are developing breastfeeding guidelines.

What if I am unhappy with how I am treated by healthcare providers while breastfeeding?

If you find your HIV specialist doctor, GP doctor or other healthcare providers are not supportive of your decision to breastfeed or if they try to 'talk you' out of breastfeeding, remember it is your right to breastfeed.

Seeking out a second or third medical opinion is also your right as a patient.

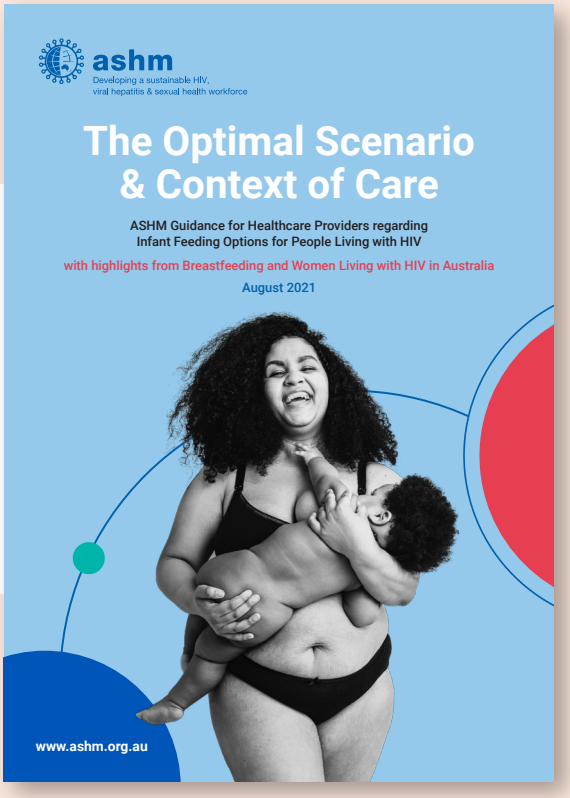
You can also remind your healthcare providers that they are required to follow a patient-centred care approach in your decision to breastfeed. Patient-centered care means treating you with dignity and respect and involving you in all decisions about your healthcare.

Patient-centred care is linked to your healthcare rights that apply to all state government healthcare providers as stipulated in the Australian Charter of Healthcare Rights, endorsed by the Health Minister in 2008, and updated in 2019.

If you continue to meet opposition, you can contact your Australian state-based PLHIV organisation for advice and speak with an HIV peer support worker or an HIV peer navigator. If you wish, they can also contact your healthcare providers on your behalf and discuss their concerns over your decision to breastfeed. They may be able to attend a meeting with you and your health care workers to support you.

Your HIV doctor will be aware of the ASHM guidance on HIV and breastfeeding. You can remind them to review this document. While your GP doctor is unlikely to know of these guidelines, you can share the online link to this document – website:

Read more



What you need to know if you are considering formula feeding your baby

The risk of HIV infection to your baby increases with 'mixed feeding', which is when commercial milk formula for babies and/or pureed solid food, in addition to breastmilk are fed to your baby. Studies show mixed feeding increases the risk of HIV transmission because mixed feeding can irritate a baby's stomach when under six months of age. An irritated stomach may allow HIV to cross into the baby's bloodstream more readily. While almost 90% of mothers begin breastfeeding in Australia, only about 15% are still exclusively breastfeeding their babies at around five months old.[5] If a mother is not breastfeeding in Australia, people will not think it is unusual and are unlikely to think it has anything to do with her being HIV positive.

Free or affordable access to baby formula may also be available through your Australian state-based HIV organisation. You can contact them to discuss how they can support you.

1. How to Prepare Formula for Bottle Feeding at Home

Read more

2. Infant Formula Preparation

Read more

3. Guide to Bottle Feeding

Read more

[5] Healthdirect Australia. *Why 4 in 10 mothers stop breastfeeding by 6 months*. 8 August 2018. This blog article quotes from the **2010 Australian National Infant Feeding Survey (ANIFS)** which gathered information about infant feeding practices and attitudes from a sample of mothers and carers in Australia. The survey gathered information about the prevalence and duration of breastfeeding and collected information on other foods consumed by infants. https://www.healthdirect.gov.au/blog/why-4-in-10-mothers-stop-breastfeeding-by-6-months

You and your baby can still have a very close bond when you are formula feeding, by having lots of eye contact and skin-to-skin contact with your baby.

What you can say if someone asks you why you are bottle-feeding

"I couldn't produce enough milk to breastfeed."

"Breastfeeding just didn't work for us."

"I had problems with breastfeeding previously."

"My baby didn't latch well."

"I am taking antibiotics."

"He/she started off on formula, so we just stuck with it."

"Formula feeding allows their father to help out more."

"I have inverted/painful nipples."

"My doctor advised me to formula feed because the baby wasn't gaining weight."

"It is a personal choice."

"I prefer the privacy."

Other options for infant feeding

Human milk banks

Women who produce more breastmilk than they need for their own baby may give the extra milk to a milk bank. This milk is screened before being donated.

To find out more about donor milk go to the website of the Australian Breastfeeding Association:

Australian Breastfeeding Association

The future of HIV and breastfeeding

The latest evidence shows that the risk of HIV transmission through breastmilk when the mother is taking HIV medications and has a sustained undetectable viral load is extremely low. Women living with HIV all around the world are advocating for more data to be collected and shared. In particular, it is important to have data from countries like Australia. The more breastfeeding mothers with HIV who participate will help strengthen the data collected for future recommendations and acceptance.

If you choose to breastfeed, please consider being included in research. Any data collected will not reveal your name. It will be anonymous. Your HIV clinic will advise you about how your data will be collected and how it will be used.

Where to find further help and support

There are a growing number of women living with HIV who have safely breastfed their babies and many are willing to share their stories of their lived experience. There are also a growing number of medical professionals who can help you if you have any breastfeeding problems as a woman living with HIV. Seek out:

- Women living with HIV who breastfed their babies
- HIV women's support organisations for information and peer support
- Medical professionals knowledgeable about women living with HIV and breastfeeding
- Breastfeeding organisations (for general advice, not HIV-related)
- Perinatal anxiety and depression support
- Further online resources with information on women living with HIV and breastfeeding

To access a listing for the above – visit:

Living Well site

If you do decide to breastfeed, please consider being included anonymously in data collection, which is vital for women living with HIV in Australia and other countries in making an informed decision on breastfeeding.

Pregnancy and breastfeeding for women living with HIV in Australia

Supplementary Referral Flowchart

HIV Clinic – HIV specialist doctor

Once your pregnancy is confirmed – your HIV specialist doctor may refer you to both:

An Infectious Diseases Specialist Doctor (who has interest and experience in HIV and pregnancy)	An obstetrician (who may have interest and experience in HIV and pregnancy)

This will depend on the Australian State or Territory healthcare system where you live.

Note: If you are referred to an infectious diseases specialist doctor (IDD), then you will usually stop seeing your usual HIV specialist doctor during your pregnancy. You will return to them after the birth of your baby (post-partum).

An infectious diseases specialist doctor provides ongoing care and management of HIV and any other infections during pregnancy.

This includes providing you with education about methods of reducing HIV transmission to your baby.

They will ensure that you are linked to a **paediatric infectious diseases team** who will prescribe the PEP antiretrovirals for your baby and manage your baby's regular blood tests after birth.

They will provide information on HIV and breastfeeding and link you to midwives/nurses or lactation experts with an interest and experience in HIV and breastfeeding.

During your pregnancy, these nurses/midwives provide education on breastfeeding. They also support you after the birth of your baby up to the first year of your baby's life as required. They also help coordinate your baby's follow-up blood tests.

Note: In Victoria, pregnant women with HIV will be linked to an HIV clinical nurse from the Victorian HIV Service 'Outward Program', who will provide support throughout your pregnancy.

An obstetrician orders routine blood tests and monitors your blood results specific to pregnancy.

They will have specialist skills to manage complex or high-risk pregnancies and births. As a woman living with HIV you will see your obstetrician more often.

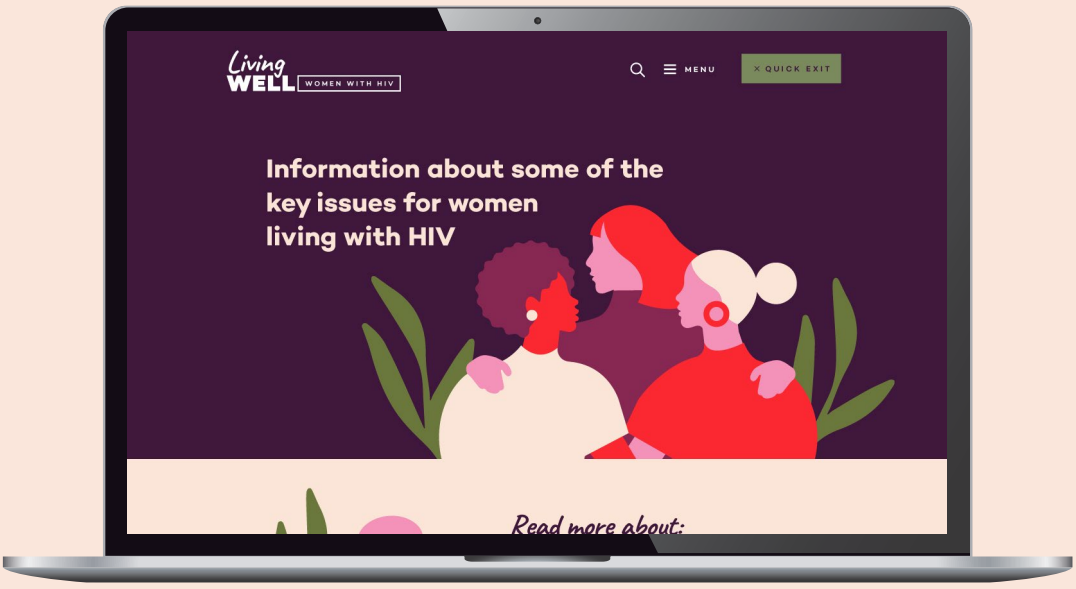
They will manage and discuss your labour and the baby's birth as either a natural birth or a caesarean.

They will see you at a hospital out-patient clinic where you will have your ultrasounds to check on your baby's growth and position. Or they may perform this in their private clinic.

They may discuss lifestyle changes that are good for your baby such as smoking cessation and stopping drinking alcohol.

Living WELL

WOMEN WITH HIV



PositiveWomen
Support and advocacy for women living with HIV

napwha national association of people with HIV australia