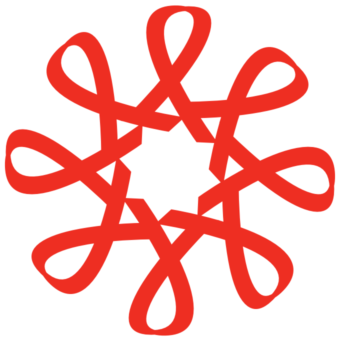
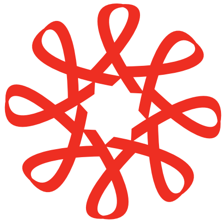


Positive Women

HIV, PREGNANCY AND WOMEN'S HEALTH

• Version 4 – Revised 2019

• INTRODUCTION • MOTHER'S HEALTH IS BEST FOR BABY
• PLANNING PREGNANCY • ANTENATAL CARE • HIV TREATMENT
• DELIVERY OPTIONS • AFTER BABY IS BORN



Positive Women

ABOUT POSITIVE WOMEN INC.

POSITIVE WOMEN INC. IS A SUPPORT ORGANISATION FOR WOMEN AND FAMILIES LIVING WITH HIV OR AIDS.

Women represent the invisible face of the HIV and AIDS epidemic. These are women who lead the very usual life of the average New Zealander. Women who run households, cook dinner, have jobs, raise families and have grandchildren.

Our Aim

- To support women and families living with HIV or AIDS in Aotearoa New Zealand
- To raise awareness of HIV and AIDS in the community through educational programmes with a focus on prevention and de-stigmatisation.

What We Do

- Provide a drop in centre in Auckland open from 9.00-5.00pm, Monday to Friday.
- Access to a free-phone number for information and support.
- A bi-monthly newsletter.
- Hold a FREE annual seminar for women living with HIV.
  The seminar is designed to help reduce isolation for women living with HIV through peer support. There are also discussion groups as well as educational and informational breakout sessions.
- Coordinate social events for women living with HIV to get together throughout the year.
- Positive Speakers training for people living with HIV to become HIV community educators.
- Family Hui every two years for women and families living with HIV.
- Annual Teen Camp for teens living with HIV.
- Services of a registered social worker.

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Adapted from UK HIV i-Base booklet on 'HIV pregnancy and Women's health', with input from the (now defunct) New Zealand National Antenatal HIV Screening Advisory Group and Positive Women Incorporated (NZ). Also with assistance from the Auckland University Medical Students and Caroline Bree, Midwife at Auckland DHB.

This booklet is intended to provide basic information and is not necessarily the views of Positive Women Inc. Decisions relating to treatment always need to be made in consultation with a doctor or other qualified healthcare workers.

INTRODUCTION

This booklet aims to help you get the most out of your own treatment and care if you are considering pregnancy. It is also an excellent resource for midwives and other medical professionals working with HIV and pregnancy.

We hope the information in this booklet will be useful at all stages—before, during and after pregnancy. It will be beneficial whether you are already on HIV treatment or not. It includes information for your own health and for the health of your baby.

REMEMBER YOU DO HAVE CHOICES AND THE BETTER INFORMED YOU ARE, THE BETTER ABLE YOU WILL BE TO MAKE THE RIGHT CHOICE FOR YOU.

You may be reading this booklet at a very confusing and difficult time. Finding out you are pregnant or that you have HIV can be overwhelming. It can be even more so if you find out both at the same time.

On an optimistic note, it is likely that no matter how difficult things seem right now, they will get better and easier. It is very important and reassuring to understand there has been a lot of progress made in treating HIV. This is especially true for treatment in pregnancy. When on medications, people with HIV are now capable of living long and productive lives and women can have babies that are not HIV positive.

Most people with HIV have time to come to terms with their diagnosis before deciding about treatment. This may not be the case if you were diagnosed during your pregnancy. You may need to make some decisions more quickly. It is important to be sure you understand the advice you receive.

Here are some tips if you are confused or concerned as you consider your options:

- Ask lots of questions
- You may want to take your partner, a member of your family/Whanau or a friend with you for support to your appointments
- Try to talk to other women who have been in your situation

The decisions you make about your pregnancy are very personal. Having as much information as possible will help you make informed choices. You can only make choices after learning all you can about HIV and pregnancy and have discussed them with your healthcare team.

Positive Women Inc is also a very valuable resource. Contact them if you want to find out more or talk with another woman living with HIV who has had a baby.

WITH HIV MEDICATIONS, THE RISK OF HIV TO A BABY BORN TO A MOTHER WITH HIV, HAS REDUCED FROM 31.5% TO LESS THAN 1%

New Zealand National Health Committee 2004

CAN WOMEN WITH HIV BECOME MOTHERS?

YES, AND HIV TREATMENT MAKES THIS MUCH SAFER

HIV medication has changed the lives of people with HIV in every country where they are used. Treatment has had an enormous effect on the health of mothers with HIV and their children. It has encouraged many women to think about having children or having more children.

Women have safely been using HIV medications in pregnancy for more than 25 years. This usually involves taking at least three types of drugs which is called, ‘Antiretroviral Therapy’ (ART) or ‘Combination Therapy’.

HIV treatment will protect your baby

The benefits of treatment are not just for your own health. Treating your HIV will also reduce the possibility of your baby getting HIV to almost zero.

How is HIV transmitted to a baby?

The exact way HIV is transmitted from mother to baby is still unknown.

Transmission of HIV is when the virus passes from one person to another. When this is from mother to baby it is called vertical transmission.

What is known is that most vertical transmission happens near the time of or during labour and when the baby is being born.

Vertical transmission can also occur through breastfeeding.

Certain risk factors can make transmission more likely. The biggest of these is the mother’s viral load. The viral load is the amount of virus which is in the blood.

The aim of taking medications is to reduce the viral load with the goal of reaching what is called an undetectable viral load. With an undetectable viral load HIV cannot be passed on to your baby.

Viral load tests measure the amount of virus in your blood. The measurements are in copies per milliliter (copies/mL).

- Undetectable viral load is currently considered to be below 50 copies/mL. When we talk about an undetectable viral load in this guide, that is what we mean.
- If a mother’s viral load is undetectable when her baby is born, the risk of vertical transmission is almost zero.

REGARDLESS OF PREGNANCY, WOMEN MUST RECEIVE OPTIMAL TREATMENT FOR THEIR HIV FIRST

Are pregnant women automatically offered HIV testing?

HIV Screening was offered to all pregnant women in New Zealand as part of a Ministry of Health, HIV Antenatal Screening programme. Due to the low numbers picked up, the programme was stopped in 2015. It was also felt that HIV testing for pregnant women had become ingrained due to the screening programme and would continue to be offered.

A number of blood tests are already offered to women when they first see their doctor or midwife during pregnancy. HIV testing has been added to this group of antenatal blood tests and is offered at the same time. (NSU,2012).

This is not a compulsory test. It is an option which you can decline or accept.

Is it safe to take HIV medicines during pregnancy?

Although pregnant women are often advised against taking medications, this is not the case with HIV treatment. This difference can sometimes seem confusing.

As with many medications, there can be side-effects of using antiretrovirals while you are pregnant, but thousands of women have taken these medicines all over the world without any complications to their baby. This has resulted in many healthy babies who do not have HIV.

Your healthcare team also has access to an international birth defect registry. This has tracked birth defects in babies exposed to antiretroviral drugs since 1989. www.apregistry.com

So far, the registry has not seen an increase in the type or rate of birth defects in babies whose mothers have been treated with antiretrovirals, compared to the babies born to mums not using these drugs.

During your antenatal discussions, you and your midwife/doctor will discuss the benefits and risks of treatment options.

CD 4 Cells

- CD4 cells are a type of white blood cell that helps our bodies fight infection. They are the cells that HIV infects and uses to make copies of itself.
- Your CD4 count is the number of CD4 cells in one cubic millimetre (written cells/ mm3 but in this guide we will just use the number eg 500) of blood.
- CD4 counts vary but an HIV negative adult would expect to have a CD4 count in the range of 400 to 1,600.).
- The drop should be a concern if your CD4 falls below 200. Below this level, you are at a higher risk from opportunistic infections.

Will being pregnant make my HIV worse?

Pregnancy does not make a woman's HIV get any worse or progress any faster. However, being pregnant may cause a drop in your CD4 count. This drop is only temporary. Your CD4 count will generally return to your pre-pregnancy level soon after the baby is born.

Women who have been diagnosed with late stage HIV or AIDS may experience opportunistic Infections. These are infections which can occur after HIV has damaged the immune system. These infections could affect the baby, and you will need to be treated for them immediately. In general pregnant women need the same treatment to treat and prevent opportunistic infections as people who are not pregnant.

If you start taking medications in pregnancy your CD4 count may not increase very much even though your viral load goes down. If this happens don't worry, your CD4 count will catch up after the baby is born.

PROTECTING MOTHER'S HEALTH

YOUR OWN HEALTH AND TREATMENT ARE THE MOST IMPORTANT THINGS TO CONSIDER FOR ENSURING A HEALTHY BABY. THIS CANNOT BE STRESSED ENOUGH.

Sometimes the health and needs of a pregnant woman with HIV can be overlooked as the focus is on the baby.

Do not forget the health and care of the mother is very important.

Antenatal discussions for women with HIV to include:

- Advice about how to prevent vertical transmission.
- Information about treating the mother's own HIV while pregnant.
- Information about treating the mother's HIV in the future.
- Your child is certainly going to want you to be well and healthy as they grow up. And you will want to be able to watch them go to school and become an adult.
- A healthy mother is vital for the health of a child.

Principles of Care

- A mother needs to be able to make informed choices about how to manage her pregnancy.
- Healthcare workers need to provide information, education and counselling that is impartial, supportive and non-judgmental.
- HIV needs to be intensively monitored during pregnancy. This is particularly important as the time of birth approaches.
- Opportunistic infections need to be treated appropriately.
- Antiretroviral drugs are recommended to reduce viral load to undetectable levels.
- Be involved in the decision making about treatment during the pregnancy.
- Mothers are to be treated in the best way to protect them from developing resistance to antiretroviral drugs.
- Mothers have the right to make informed choices regarding how and when their babies will be born.

HOW HIV IS TRANSMITTED TO A BABY

Explanation of terms

In utero is within the uterus or womb before the start of labour.

Intrapartum means occurring during delivery (labour or child birth).

Placenta is a temporary organ that develops in pregnancy and joins the mother and fetus. The placenta acts as a filter. It transfers oxygen and nutrients from the mother to the fetus and takes away carbon dioxide and waste products. The placenta is full of blood vessels. The placenta is expelled from the mother's body after the baby is born and it is no longer needed. It is sometimes called the afterbirth.

Maternal-fetal microtransfusions are when small amounts of infected blood from the mother leak from the placenta to the baby during labour (or other disruption of the placenta).

Fetoplacental circulation is the blood supply in the fetus and placenta.

Fetal membranes are the membranes surrounding the fetus.

Chorioamnionitis is inflammation of the chorion and the amnion, the membranes that surround the fetus Chorioamnionitis is usually caused by a bacterial infection.

Mucosal lining is the moist inner lining of some organs and body cavities (such as the nose, mouth, vagina, lungs, and stomach). Glands in the mucosa make mucous, a thick slippery fluid. A mucosal lining is also called a mucous membrane.

Gastrointestinal (GI) tract is the tube that runs from the mouth to the anus and where we digest our food. The gastrointestinal tract begins with the mouth and then becomes the oesophagus (food pipe), stomach, duodenum, small intestine, large intestine (colon), rectum and finally the anus.

How and why does transmission happen?

Despite remarkable achievements in reducing vertical transmission, we do not fully understand how it happens. What we do understand is that there are many factors which affect transmission. Of these, the level of the mother's viral load is the most important.

Vertical transmission of HIV can happen before, during or after birth. Scientists have found several possible reasons for infection. Besides the mother's viral load, her low CD4 count and whether she has other infections can make it more likely.

The exposure of the baby to a mother's infected blood or other body fluids during pregnancy and delivery, as well as breastfeeding, are thought to be how transmission happens. Most transmissions happen during birth, when the baby is being born. More rarely, some transmissions happen during pregnancy before delivery. This is called in utero transmission.

Transmission during pregnancy (in utero)

This may happen if the placenta is damaged, making it possible for HIV-infected blood from the mother to transfer into the blood circulation of the fetus.

Chorioamnionitis for example, has been associated with damage to the placenta and increased transmission risk of HIV.

This is thought to happen either by infected cells traveling across the placenta, or by progressive infection of different layers of the placenta until the virus reaches the fetoplacental circulation.

The reason we know that in utero transmission happens is because a proportion of babies have been tested when they are a few days old and already have detectable virus in their blood. Usually it takes several weeks from when someone is infected until HIV shows in the blood. The rapid progression of HIV disease in some babies has also led scientists to conclude that in utero transmission happens.

Having a high viral load and a low CD4 make in utero transmission more likely. (Optimal is low viral load and high CD4).

Having TB (tuberculosis) at the same time also makes it more likely, and HIV makes in utero transmission of TB more likely.

Transmission during labour and birth

Transmission during birth is thought to happen when the baby comes into contact with infected blood and genital secretions from the mother as it passes through the birth canal.

- This could happen through ascending infection from the vagina or cervix to the fetal membranes and amniotic fluid, and absorption in the digestive tract of the baby.
- Alternatively, during contractions in labour, maternal-fetal microtransfusion may occur.

Scientists know that transmission occurs during birth because:

- There is a rapid increase in the rate of detection of HIV in babies during the first week of life.
- The way that the virus and the immune system behave in some newborn babies is similar to that of adults when they first become infected.
- The success of treatments that have reduced transmission risk, even when given only in labour and delivery of the baby by Caesarian section before labour starts.

A premature baby may be at higher risk of HIV transmission than a full term baby.

Transmission through Breastfeeding

- HIV in breast milk most likely gets through the mucosal lining of the gastrointestinal tract of infants. The gastrointestinal tract of a young baby is immature and more easily penetrated than that of an adult. It appears damage to the intestinal tract of the baby, caused by the early introduction of other foods, particularly solid foods, may increase the risk of infection.
- See page 24 for more information on breastfeeding.
- Positive Women Inc have a resource called 'Feeding Options for Babies whose mother have HIV' which may also be helpful.

PLANNING YOUR PREGNANCY

Pre-conception; Planned pregnancy, and your rights to have a baby

For women who choose to become pregnant after contracting HIV

If you already know you have HIV, you may have discussed the possibility of becoming pregnant as part of your routine HIV care, whether this pregnancy was planned or not.

If you are planning to get pregnant, your healthcare provider will advise you to:

- Consider your general health.
- Have appropriate checkups.
- Treat any sexually transmitted infections (STIs).
- Make sure you are receiving appropriate care and treatment for you HIV
- Choose a Lead Maternity Carer (LMC) and health care team who support and respect your decision to have a baby.

When both partners have HIV

For couples in which both partners have HIV, some doctors still recommend sex with condoms to limit the possibility of re-infection with a different strain of HIV (or a resistant strain).

Re-infection is only a risk if one partner has extensive drug resistance and a detectable viral load, or neither partner is on ART. This should be the only reason that a couple in this situation might be discouraged to attempt to conceive naturally.

All these options involve very personal decisions. Knowing and judging the level of risk is also very individual. All methods of becoming pregnant carry varying degrees of risk and chance of success.

If you are planning a pregnancy, take the time to talk about these options with your partner. This way you can make decisions that you both are happy with.

When one partner has HIV and the other does not

There has been good news for couples in this situation.

A person living with HIV who is on antiretroviral therapy and has an undetectable viral load for at least six months will not sexually transmit HIV to their negative partner when having sex without a condom.

Undetectable=Uninfectious (U=U)

Undetectable is when a person living with HIV is on HIV Medication which has reduced the amount of virus in their blood to an undetectable level.

Unifectious is when a person living with HIV has an undetectable viral load which means they cannot sexually transmit HIV to their partner, or to their baby through pregnancy.

An undetectable viral load occurs when medication reduces the amount of HIV in a person's blood to the point where it is so low it cannot be detected in a blood test. Having an undetectable viral load enables the immune system to regenerate and improves the health of a woman living with HIV. It also reduces the chance of transmitting HIV to her baby to less than 1%.

Maintaining U=U requires taking medication as prescribed.

What is the Evidence?

The safety of U=U has been confirmed by worldwide research including PARTNER, HPTN 052, Opposites Attract and the Swiss Statement.

In the recent PARTNER study, there were zero transmissions out of 58,000 condomless sexual acts between people with HIV and their partners who are HIV negative. (www.bodypositive.org.nz). For many people these developments are very reassuring, particularly those who meet the medication and viral load conditions and choose to have sex without condoms.

Couples who generally use condoms will be advised that the recommended way of conception is by timed intercourse when the woman is most fertile

When the woman has HIV and the man is HIV negative

The recommendation is for the woman to commence antiretrovirals and after six months with an undetectable viral load, she is uninfectious at which point it would be safe to have unprotected sex to get pregnant without transmitting HIV to her partner.

Do-it-yourself self-insemination with a plastic syringe carries zero risk to the man. Around the time of ovulation place your partner's semen as high as possible into your vagina using a plastic syringe. Your healthcare team can provide a syringe and container.

When the woman is HIV negative and the man has HIV

If the man is on antiretroval medications and has an undetectable viral load for six months or more, this will make him uninfectious, which means it would be safe to have unprotected sex at no risk of passing on HIV to his partner.

Sometimes a woman planning pregnancy may not know her partner's HIV status, viral load or adherence history. She can discuss her plans and concerns with her healthcare team.

Pre-exposure Prophylaxis (PrEP) is when an HIV negative person takes antiretrovirals to prevent them from getting HIV. This method is sometimes recommended to help make a conception safer. PrEP for this situation is not currently (2016) funded in New Zealand.

Some couples might also be anxious about transmission with unprotected intercourse even though they meet the medication, adherence and viral load conditions. In these cases, they may wish to consider other methods.

Can I get help if I am having difficulty conceiving?

All couples can experience fertility difficulties, regardless of whether they have HIV or not. There are things you can do which have been known to have some success.

If you have fertility problems, ask your doctor about assisted reproduction and the possibility of referral to a fertility clinic which has experience of working with people who have HIV.

Is fertility treatment available to people living with HIV?

Yes. Fertility is important when trying for a baby whether or not you have HIV. The same fertility support services should be provided for people living with HIV as for people who don't have HIV.

There will also be the same levels of screening given to you as any couple accessing fertility treatment. These can be quite strict.

You may encounter resistance to this help because you have HIV. You can and should complain about this. You may want to choose a clinic that is more empathetic, or perhaps a clinic that has more experience with parents who have HIV.

Fertility Plus, the clinic associated with Auckland District Health Board is located at the Greenlane Clinical Centre. It has developed protocols for treating couples where one or both partners have HIV, which are approved by the national ethics committee.

If you are living outside Auckland it may be helpful for you to ask your doctor to refer you to the local clinic. The staff there can contact Fertility Plus on (09) 630-9810 to discuss what services they offer

Timing of conception attempt

Ovulation – the most fertile time during a woman's menstrual cycle is when a mature egg is released from her ovary. The egg has a life span of about 24 hours. Conception is most likely to take place at this time.

Ovulation usually occurs about 14 days before the beginning of the woman's next menstrual cycle.

You are at your most fertile the day before and the day of ovulation. This is when conception can take place.

The fertile period is usually about 5 days before ovulation (as sperm can survive in your body for several days) until about 2 days after ovulation. So the period that a woman is fertile is about 7 days.

There are different ways to estimate your fertile time, usually by taking your temperature (which increases at the beginning of ovulation), or by recording when you have your periods, in order to work out when you are ovulating (called the calendar method).

Your healthcare team can explain how to do this.

HIV CARE AND TREATMENT DURING PREGNANCY

What is antenatal care?

This covers all the care that you receive during your pregnancy in preparation for your baby's birth.

Antenatal care is not only about medicine and tests. It includes counseling and providing information like this booklet. It also includes advice on your general health such as diet, exercise and stopping smoking.

As with all aspects of HIV care, it is important that members of your healthcare team have experience with HIV positive women. (i.e. your obstetrician, midwife, paediatrician and other support staff).

It is also important that the people responsible for providing your care understand the most recent developments in preventing vertical transmission and in HIV care.

Antenatal relates to the period before a baby's birth, the time in which the fetus (developing baby) grows in the uterus.

Does every woman living with HIV need to use treatment in pregnancy?

In New Zealand all pregnant women with HIV are recommended to start medication. Some women living with HIV will already be on medication when they become pregnant.

Treatment recommendations for pregnant women can be slightly different than those for other adults living with HIV.

Usually it is best once you start HIV treatment, to continue for the rest of your life.

What if I am already using HIV treatment when I become pregnant?

Many women decide to have a baby when they are already on medication. Women feel better. They are healthier. They are thinking about long-term relationships. They are thinking about a future and possibly a family.

It is now increasingly common for women who conceive while they are on treatment to continue on treatment throughout their pregnancy. Studies have not shown any increased risk to the mother or baby from using continuous treatment throughout the pregnancy.

It is recommended that women conceiving on an effective ART regimen should continue this.

What if I need treatment for my own HIV?

If you are diagnosed early on in your pregnancy, you may choose to delay starting treatment until the end of the first trimester. This is the first 12 to 14 weeks from your last missed period. You might also want to delay treatment over this period if you already know your HIV status but have not yet started treatment.

There are two main reasons for delaying treatment:

The first is that the baby's main organs develop in the first 12 weeks in the womb. This is called organogenesis. During this time a baby might be vulnerable to negative effects from any medicines, including antiretroviral drugs. Although there is data to show that antiretrovirals are generally safe.

A second reason is that some women may experience nausea or "morning sickness". Symptoms of morning sickness are very similar to the nausea that can occur when starting ART. This can also make adherence harder. If you have morning sickness you might delay starting treatment until after the first trimester.

Most women will have started medication by 24 weeks of pregnancy. This will mean you have the time to get your viral load to undetectable before the baby is born. That way you have the least risk of transmission and you will be able to have a vaginal birth.

If you are diagnosed at 28 weeks or after it will be recommended to start medication straight away. If your CD4 count is very low and your viral load high and/or you have an opportunistic infection, or you are diagnosed late in pregnancy, medication should not be delayed.

What drugs will I start with if I'm in this situation?

ART usually consists of two drugs called nucleoside or nucleotide reverse transcriptase inhibitors (NRTI) as a backbone, plus a third one, which is either a non-nucleoside reverse-transcriptase inhibitor (NNRTI) or a boosted protease inhibitor (PI).

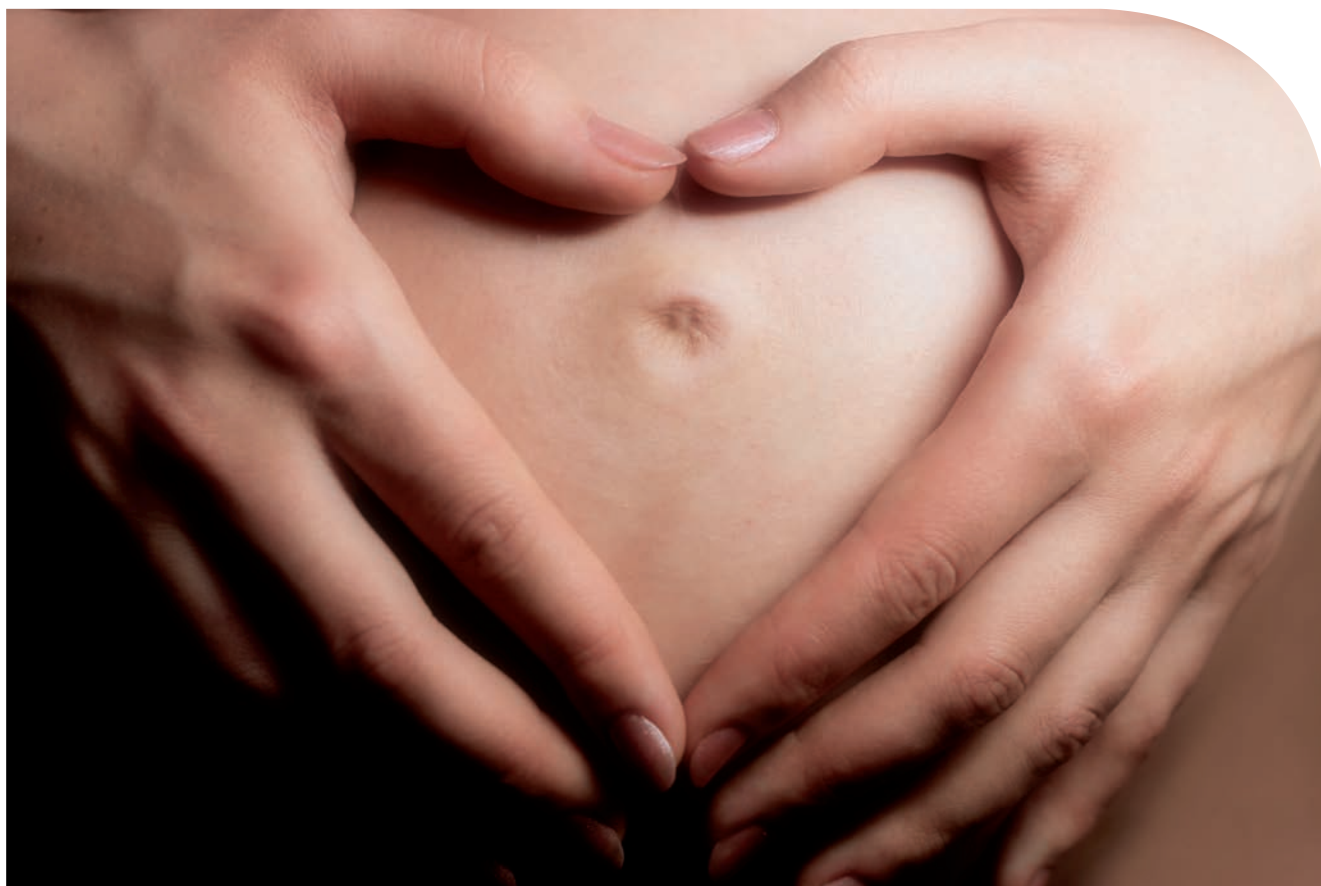
The AZT and 3TC (Combivir) NRTI backbone has been used the most (so has the most information about it) in pregnancy, so some doctors prefer to recommend this. But tenofovir and FTC (Truvada), and ABC and 3TC (Kivexa) are now more widely used in pregnancy, and are also good options.

A European study looked at use of non-AZT ART in pregnant women. About 60 percent of women received this in the study. There were no greater rates of vertical transmission, undetectable viral load at delivery or abnormalities in the babies for women who received non-AZT ART.

The third drug for women in this situation will usually be an NNRTI (efavirenz or nevirapine) or a ritonavir boosted PI.

Efavirenz was not previously recommended in pregnancy because the drug caused neural tube (the developing brain) damage to a fetus in a single animal study. Efavirenz has now been used and studied a lot in pregnancy and does not appear to be more risky than any other antiretroviral in humans. The British HIV Association and several other guidelines recommend it in pregnancy.

Recommended boosted PIs are lopinavir (boosted lopinavir is called Kaletra and in one pill) and atazanavir.



What if I discover I have HIV late in pregnancy?

Diagnosis after 28 weeks of pregnancy, before labour starts, is happening less frequently since HIV screening for pregnant women was introduced.

But if this happens to you, there is plenty that can be done to help you have a negative baby.

As viral load testing can now be turned around quickly, some women will still be able to have a vaginal birth (if they start ART immediately and get an undetectable viral load in time).

If a woman's viral load is unknown when she starts treatment or above 100,000 copies/mL, a fourth drug, an integrase inhibitor called raltegravir, might be added to the three-drug ART regimen.

Raltegravir drives the viral load down to undetectable levels very quickly.

What if my HIV is only discovered when I am in labour?

Even at this stage there are things that can be done.

A woman in this situation will be given a single dose of nevirapine immediately. There will probably not be time to do a CD4 test but even at higher CD4 counts there are no risks to the mother's liver with a single dose alone. ART of 3TC and AZT in a single pill and raltegravir should also be given straight away.

Both nevirapine and raltegravir cross the placenta very rapidly.

Intravenous (by injection into a vein) AZT throughout labour and delivery might be added as well.

If the mother goes into labour prematurely she might also be given a double dose of tenofovir. This is because preterm babies are not able to absorb medicines very well when they are given them by mouth. Like nevirapine and raltegravir, tenofovir crosses the placenta very quickly.

Some medications are not recommended in pregnancy. Your healthcare team will be able to advise on the latest research.

Should I expect more side effects when I am pregnant?

Approximately 80% of all pregnant women using ART will experience some sort of side effects with these drugs. This is similar to the percentage of people using HIV treatment who are not pregnant.

Most side effects are minor and usually resolve quickly. They include nausea, headache, feeling tired and diarrhoea. Sometimes, but more rarely, they can be very serious.

One big advantage of being pregnant is the thorough monitoring at regular clinic visits. This will make it easier to discuss any side effects with your doctor.

Some side effects of antiretrovirals are very similar to the changes in your body during pregnancy, such as morning sickness. This can make it harder to tell whether treatment or pregnancy is the cause.

HIV medicines can cause nausea and vomiting. You may feel more tired than usual. Again, this is to be expected, especially if you are starting ART and pregnant at the same time. Anaemia (low red blood cells) can cause tiredness. It is a very common side effect of both medication and pregnancy. A simple blood test checks for this. If you have anaemia you may need to take iron supplements.

All pregnant women are at risk of developing high blood sugar (hyperglycemia) and diabetes during pregnancy. Women taking protease inhibitors in pregnancy have a higher risk of this common complication. So, you should be sure to have your glucose levels closely monitored and be screened for diabetes during pregnancy. This is routine for all pregnant women.

Outside of pregnancy, protease inhibitors have been associated with increased levels of bilirubin. While this is usually a measure of the health of your liver this is not always the case as with the PI atazanavir. Here bilirubin levels can be very high but without causing any problems.

Pregnancy may be an additional risk factor for raised levels of lactic acid. Your liver normally regulates this.

Lactic acidosis is a rare but dangerous and potentially fatal side effect of nucleoside analogues. Using d4T and ddI together in pregnancy appears to be particularly risky for lactic acidosis. This combination is now not recommended in pregnancy Consequently the risk of lactic acidosis is now extremely low.

SOME HELPFUL TIPS...

Tips to help with adherence

First of all, get all the information on what you will need to do before you start treatment:

- How many tablets?
- How often do you need to take them?
- How exact do you have to be with timing?
- Are there food or storage restrictions?
- Are there easier choices?

Divide up your day's drugs each morning and use a pillbox. Then you can always check whether you have missed a dose.

Take extra drugs if you go away for a few days.

Keep a small supply where you may need them in an emergency. For example, in your car, at work or at a friend's.

Get friends to help you remember difficult dose times or when you go out at night.

If you have a mobile phone with a calendar, you can set the calendar to remind you to take your pills at the same time every day.

If you have a computer, you can set the computer calendar to remind you at the same time each day.

If you need an online calendar service, like Google, you can set it to remind you every day. Some online calendars, including Google, can sms you at the same time every day.

Ask people already on treatment what they do. How well are they managing?

Positive Women Inc. can arrange for you to talk to someone who is already taking the same treatment if you think that would help.

Make sure you contact your hospital or clinic if you have serious difficulties with side effects. Staff members there can help and discuss switching treatment if necessary.

Tips to help with morning sickness or drug-associated nausea

- Eat smaller meals and snack more frequently rather than eating just a few larger meals.
- Try to eat more bland foods. Avoid foods that are spicy, greasy or strong smelling.
- Leave some dry crackers by your bed. Eat one or two before you get up in the morning.
- Ginger is very helpful. It can be used in capsule or as ginger root powder. Fresh root ginger peeled and steeped in hot water can help.
- If cooking smells bother you, keep the room well ventilated. Microwave meals prepare food quickly and with minimum smells. They also help you eat a meal as soon as you feel hungry. Getting someone else to prepare your meals can help.
- Don't eat in a room that is stuffy or that has lingering cooking smells.
- Eat meals at a table rather than lying down. Don't lie down immediately after eating.
- Try not to drink with your meal or straight after. It is better to wait an hour and then sip drinks.
- It is important for pregnant women not to become dehydrated though, so do remember to drink outside mealtimes.
- Try eating cold rather than hot food. Or let hot food cool well before you eat it.
- Peppermint is also useful. It can be taken in tea or in chewing gum

SCREENING AND MONITORING

Will I need extra tests and monitoring?

Both pregnancy and HIV require careful monitoring.

If you start ART in pregnancy it is recommended to have a viral load test 2 to 4 weeks after starting, at least one every trimester, at 36 weeks and delivery.

A liver function test will also be done when you start ART and then at each antenatal visit.

If you do not achieve an undetectable viral load by 36 weeks some doctors may recommend therapeutic drug monitoring. TDM uses blood tests to check whether you are absorbing the correct amount of a drug. Drug levels, particularly of PIs, can vary greatly between women and can be lower during pregnancy. Occasionally this can lead to a dose adjustment.

Your doctor will also discuss your adherence with you and perhaps do another resistance test. You might need an adjustment to your regimen.

In addition to your HIV care you will be screened for hepatitis, syphilis and other STIs, anaemia and tuberculosis (TB).

Antenatal screening includes blood pressure, weight, blood and urine tests as well as fetal monitoring. Unless you need extra care you will probably visit your clinic monthly for most of your pregnancy and every week after the eighth month.

Opportunistic Infection prevention and treatment during pregnancy

Treatment and prophylaxis for most opportunistic infections during pregnancy is broadly similar to that for non-pregnant adults. Only a few drugs are not recommended.

You may need to be treated for other infections, especially if you are diagnosed with HIV during pregnancy.

Prophylaxis and treatment of Pneumocystis carinii pneumonia (PCP), Mycobacterium avium complex (MAC) and tuberculosis (TB) infections are recommended if necessary during pregnancy.

Prophylaxis against cytomegalovirus (CMV), candida infections, and invasive fungal infections is not routinely recommended because of drug toxicity.

Treatment of very serious infections should not be avoided because of pregnancy.

PREVENTION AND TREATMENT OF OTHER INFECTIONS

Vaccine use while pregnant

Pregnant women may be offered the flu vaccine (containing season and H1N1 vaccines).

Hepatitis A (HAV), hepatitis B (HBV) and pneumococcal vaccines may also be used during pregnancy.

Live vaccines including measles, mumps and rubella should not be used during pregnancy.

Hepatitis B co-infection

It is very likely that mothers with active hepatitis B virus (HBV) will transmit to their babies (90%). However, transmission can be prevented by immunising the baby against HBV shortly after he or she is born. This is standard practice in the New Zealand.

If you have HBV you will need to take an ART regimen that includes tenofovir and either FTC or 3TC as they act against HBV as well as HIV.

You will also be vaccinated against HAV after the first trimester.

Women with hepatitis co infections will be seen by a liver specialist as well as their HIV medical team.

Hepatitis C co-infection

If you are co-infected with hepatitis C virus (HCV) and HIV—you may discover this through routine screening in pregnancy—there is a risk of transmission of HCV of between 15% to 18% when the mother also has HIV. Treating your HIV will reduce this risk of transmitting HCV. You will need to take ART regardless of your CD4 count.

Mothers with HCV should not be treated with pegalated interferon or ribarvirin. If you discover you are pregnant while being treated with these drugs, they should be stopped. Your HCV will need to be carefully monitored. You will be vaccinated against HBV and HAV.

TB co-infection

It is important to treat TB in pregnancy. Additionally HIV/ TB co-infection increases the risk of vertical transmission of both infections. TB can also increase the risk of the less common in utero (in the womb rather than during labour) vertical transmission of HIV.

Like HIV, TB is a much greater risk to a pregnant woman and her infant than its treatment or prophylaxis.

Most first line TB drugs are safe to use in pregnancy. However the TB drug streptomycin is not recommended in pregnancy as it can cause permanent deafness in the baby. This drug is not recommended during pregnancy in New Zealand (Ministry of Health, 2011).

Genital Herpes during pregnancy

Some women with HIV may also have genital herpes. Mothers with HIV are quite likely to experience an outbreak of herpes during labour. To reduce this risk, prophylaxis treatment for herpes with acyclovir is often recommended. This is safe to use during pregnancy.

Herpes is very easily transmitted from mother to child. Even if someone has a HIV viral load that is below detection on combination therapy, herpes sores contain high levels of HIV. The herpes virus can also be released from the sores during labour. This will put the baby at risk from neonatal herpes and at increased risk of HIV. Delivery by caesarian section may be recommended if there is concern about active genital herpes infection.

THE BIRTH OF YOUR BABY

Can I have a vaginal delivery?

Mothers on ART with an undetectable viral load at 36 weeks of pregnancy, and no other complications, are able to deliver vaginally.

It is recommended that decisions about the way you deliver your baby – called mode of delivery – are made at 36 weeks after a review of your viral load results.

Can I have a vaginal birth if I have had a Caesarian before?

If your viral load is undetectable, and there are no other reasons to have one, this can be carefully managed by your healthcare team. In HIV negative women, 70 percent of those in this situation manage a vaginal delivery.

Why is a Caesarian sometimes recommended if you are HIV positive?

Several early studies showed that planned Caesarian significantly reduced vertical transmission compared to vaginal birth. But these studies were before ART and viral load testing were routinely used.

For mothers on medication with an undetectable load, having a planned Caesarian does not offer any extra benefit (unless she needs one for another reason).

If you do have a planned Caesarian, the operation must be carried out before the onset of labour and ruptured membranes. This is also called "pre-labour" "elective" or "scheduled" Caesarian.

When should I have a planned Caesarian?

If your viral load is detectable at 36 weeks you should consider a planned Caesarian. Your midwife/doctor will discuss your most recent and previous viral load results, how long you have been on treatment and your adherence with you. Your own preference is important in this decision.

If your viral load is above 400, a Caesarian may be recommended.

If the planned Caesarian is to prevent vertical transmission it will happen at 38 to 39 weeks of pregnancy.

What if my waters break before my planned Caesarian?

If your waters break before your planned Caesarian is due and your viral load is not undetectable your midwife/doctor will discuss an emergency Caesarian.

Will having a Caesarian stop me having a vaginal birth in the future?

If you have a Caesarian now, having a vaginal birth in the future is possible but can be more complicated. This is important to know if you plan to have more children in a country where planned Caesarian is not possible, safe or easily available and there is less access to obstetric care.

What is the likelihood of complications?

Caesarian is major surgery, therefore complications, particularly bleeding and infections, are more common in women having Caesarians.

Caesarians appear to carry a slightly greater risk of complications among HIV-positive women compared to HIV-negative women. The difference is most notable in women with more advanced disease.

Babies delivered by elective Caesarian at 37 to 39 weeks are more likely to receive breathing support for respiratory difficulties than those born naturally at 39- 41 weeks.

Can I have a home birth?

Yes. It may be a little more difficult to find a midwife who will do this as home births for women living with HIV are not yet a common practice, but it has and can be done.

You can discuss this with your LMC or contact Positive Women Inc. for more information.

How do I make a decision?

The first thing to remember is that you have the right to choose how you give birth to your baby. Your midwife, doctor and other caregivers must respect and support your decision.

Before making a choice, though, it is important you are informed of the risks and possible benefits associated to which ever delivery mode you decide on. Spend time discussing any concerns you have with your healthcare team.

It is also important that you and your doctor make sure your HIV is well managed and your viral load is undetectable. This is not only for the risk of transmission but for your own health.

Is there anything else that I should remember for the birth?

Many books on pregnancy recommend you pack a bag or small suitcase in advance. This is especially important if you choose a natural, unscheduled delivery.

Include pyjamas or something to wear in hospital, a toothbrush, wash bag and of course your antiretrovirals.

Remember to bring all your medication with you even if you are not sure you are in labour. It is important you remember to take all your drugs on time as usual, including the day of delivery or planned Caesarian. This is a critically important time to make sure you don't miss any doses. Remembering to do so can be difficult with everything going on, particularly if you are waiting for a long time.

Make sure your partner or friend and most importantly your healthcare team, know your medication schedule, where you keep your medication, and feel comfortable helping you to remember to take your pills on time.

HIV DRUGS AND THE BABY'S HEALTH

In the past, some mothers and doctors have been reluctant to use or to prescribe antiretrovirals during pregnancy. This is out of concern about unknown effects to the baby. It is difficult to know if there are any very long-term effects.

Careful follow-up of children exposed to AZT has not shown any differences compared with other children in tests and research conducted so far.

All children born to women with HIV in New Zealand are being monitored. This close monitoring will provide important safety information in the future.

Ultimately, it seems clear that the biggest risk to a baby born to a mother with HIV is HIV itself. Antiretrovirals can prevent this.

Will Antiretrovirals affect the baby?

These concerns are justifiable. Unfortunately, there are no definite answers, but the available evidence so far shows that the drugs appear to be safe.

Some studies have looked at the risk of prematurity, birth defects and mitochondrial toxicity in babies.

Prematurity

Several studies show a greater risk of prematurity (baby born at less than 37 weeks) and low birth weight for babies born to mothers taking ART with three or more drugs and particularly with PIs. A British study found an overall rate of 13 percent (normally the rate is about 6 to 8 percent).

This should not be a reason for a mother to avoid treatment in pregnancy. It is important to be aware of the risks and options, and discuss them with your healthcare team to make sure you are receiving the best possible treatment, care and monitoring for yourself and your baby.

Can antiretrovirals cause birth defects?

There have been very few reports of birth defects in babies whose mothers have taken these drugs in pregnancy.

What about anaemia?

Anaemia (low red blood cells) has been reported in babies born to mothers on antiretrovirals but this passes quickly and rarely requires a transfusion.

What about bilirubin?

The levels of bilirubin, which can cause jaundice in the baby, may also be higher than normal with atazanavir. Your healthcare team will follow your baby's bilirubin levels very carefully and may give the baby phototherapy to reduce the levels of bilirubin. Although extremely high levels of bilirubin may damage a baby's developing brain, there have not been any reports of this occurring with atazanavir.

Will my baby be monitored for these symptoms?

Yes. Babies born to mothers with HIV on treatment will be monitored very carefully.

AFTER THE BABY IS BORN

What will I need to consider for my own health?

Adherence. This means taking your HIV medications exactly as prescribed. Adherence to your medication after the baby is born is critical.

Many women have excellent adherence during their pregnancy. After the baby is born, however, it is easy to forget your own health.

This is hardly surprising. Having a new baby can be a huge shock and is always unsettling. Your routines will change, and you are unlikely to get enough sleep. In serious cases women can have postnatal depression.

You will need lots of extra support from your family, friends and midwife. You may also find a community group very helpful.

Many mothers find the best way to remember to take their own medication is if they link it to the dosing schedule of their new baby. So, if your baby has two doses a day and you have two doses, make sure that they are taken at the same time.

How and when will I know that my baby is HIV-negative?

Babies born to mothers with HIV will always test HIV-positive at first if the usual antibody tests are used. This is because they share their mum's antibodies.

If your baby is not infected with HIV these antibodies will gradually disappear. This can sometimes take as long as 18 months.

The best test for HIV in babies is very similar to a viral load test. Called an HIV PCR DNA test, it looks for virus in the baby's blood rather than at immune responses.

Good practice is to test babies the day they are born, and then when they are six weeks and three months old.

If all these tests are negative and you are not breastfeeding then your baby will not have HIV.

You will also be told that your baby no longer has your antibodies when they are 18 months old. This exciting milestone is called seroreversion.

Will my baby need to take antiretrovirals after they are born?

Your baby will need to take antiretrovirals for two to four weeks following their birth.

The most likely drug will be AZT, which must be taken twice a day. In a few cases your baby may be given another drug or a combination of antiretrovirals, if you have a virus that is resistant to AZT, or if your baby was born while you still have a detectable viral load.

As we suggested earlier, try and co-ordinate the baby's antiretrovirals with your own treatment schedule.

Will I need to use contraception after the baby is born?

You will be given advice on contraception after your baby is born.

It is possible that resuming or beginning oral contraception will not be recommended if you begin using antiretrovirals in pregnancy.

This is because some antiretrovirals can reduce the levels of some oral contraceptives, which means they would not be foolproof birth control.

Please make sure your doctor knows about this and can advise you.

To check the baby is HIV negative: HIV PCR DNA – a polymerase chain reaction (PCR) test is a highly sensitive test that detects tiny amounts of HIV DNA in blood plasma.

The test will "amplify" or multiply the DNA so that it can be more easily detected.

FEEDING YOUR BABY

HOW CAN I GET THE BEST SUPPORT DURING THE FIRST WEEKS OF MOTHERHOOD?

Women living with HIV are likely to be cared for by a Lead Maternity Carer midwife who will support them during their pregnancy and after their baby is born.

You can find a midwife at www.findamidwife.org.nz/how-to-find-a-midwife/ or your family, friends and healthcare team may recommend a midwife.

Your midwife and healthcare team will have offered information during your pregnancy about feeding your baby. This information, and advice from others, may seem confusing and contradictory. Some women have experienced pressure to either avoid breastfeeding or to breastfeed their baby.

The Ministry of Health recommendations are for a woman to be supported in informed choice about feeding options. Understanding your options includes being aware of the benefits and possible risks of breastfeeding and infant formula.

The news of U=U led to optimism that breastfeeding would also be safe for women with HIV who had an undetectable viral load. The most recent research by the WHO and BHIVA (2017) reported a probable transmission risk of less than 1% but could not verify zero risk.

The reason is thought to be high levels of HIV in the Immune cells of breastmilk, the large volume of breastmilk ingested and the highly permeable nature of a baby's digestive tract.

The MOH currently recommends that mothers who have HIV avoid breastfeeding regardless of their viral load or treatment. However, if a mother chooses to breastfeed, she will be fully supported in doing so.

Mother to child transmission of HIV is now very rare in New Zealand. Taking antiretroviral therapy in pregnancy, careful antenatal monitoring, appropriate birthing support and feeding with infant formula milk have all contributed to excellent low rates.

Breastfeeding: The World Health Organization (WHO) infant feeding guidelines for women in countries where replacement feeding is not safe or available, recommend that breastfeeding is safer if the mother or the baby receives antiretrovirals.

Is there any way I can use my own breast milk?

If you do decide to breastfeed it is important you do not also formula feed at the same time as this is a greater risk to your baby getting HIV. It is also vital that you continue taking antiretrovirals, so your viral load remains un-detectable.

There are times when your milk will be more risky, such as if you have cracked or bleeding nipples, mastitis or thrush. There are times when your baby will be more vulnerable, such as if they have thrush or any cuts or sores in their mouth.

There is also a higher risk when the baby is weaning (having other foods alongside your breast milk). Your baby is also at higher risk if you regularly miss your antiretroviral medication or they miss theirs.

At these times it might be recommended to pasteurise (heat treat) the breastmilk. The most common method of doing this is called "flash heating".

You may be able to use a combination of flash heating and donor milk to get through any times when breastfeeding is higher risk. You may need support and advice to work through these times.

For more information refer to the Positive Women Inc. brochure 'Feeding Options for Babies whose mothers have HIV'.

Positive Women Inc. can also provide contact details of a midwife or mother living with HIV for further support.

Bottle-feeding and formula milk

Mothers with HIV should be supported to formula feed their babies if that is their informed choice. There is a big push for 'Breast is Best' in hospital settings, which can be distressing for mothers who are advised not to breastfeed when hospital staff do not know why a woman can't. They don't need to know why you are not breast feeding. It is your choice.

In New Zealand, infant formula is not subsidised for babies whose mothers have HIV so this is an added expense for the mother/whanau.

Medical treatment and provision of formula will be in confidence. Make sure you take advantage of this if you need to.

You can discuss with your midwife whether you need extra support and what is available to you when you are discharged from the hospital.

Positive Women Inc. may also be able to assist with access to infant formula.

Can I breastfeed occasionally?

It is very strongly recommended that you do not breastfeed occasionally. In fact, studies have shown that "mixed feeding" carries an even higher transmission risk than if you breastfeed exclusively.

Sometimes people ask me why I do not breastfeed

Sometimes mothers can be worried that being seen to be bottle-feeding will identify them as having HIV. It is up to you whether or not you tell anyone that you have HIV.

If you do not wish to tell anyone you are not breastfeeding because you have HIV, your doctor or midwife can help you with reasons to explain why you are bottle feeding.

For example, you can say you have cracked nipples or that the milk didn't come, both of which are common. In New Zealand some women simply prefer to bottle feed.

You are NOT a bad mother if you do not breastfeed.

Some mothers worry that if they don't breastfeed their babies they will not feel so close to them or bond with them properly. We recommend that all mothers spend some time each day holding their babies in 'skin to skin' contact – baby's naked body between the mother's naked breasts with a sheet or blanket covering them both. Regardless of how baby is fed, this is a lovely way to feel close to your baby, and to let your healthy skin microbes help to protect your baby's skin.

When you are pregnant you may notice lots of information promoting breastfeeding. Some women feel guilty about not breastfeeding their babies. When you have had the opportunity to discuss the options and you have made a decision, let yourself off the hook and try not to carry around bad feelings.

Your wishes and feelings are important. You must be comfortable with the decisions you make. After all, there are many aspects to being a great parent, and the most important thing is being able to love and enjoy your baby.

Other feeding options.

Infant feeding decisions are often fraught with emotion for mothers. Women living with HIV may need to talk through their feelings about this.

Infant formula is not the only option if a mother decides not to feed at the breast. Some mothers choose to use another mother's donated breast milk. This will take some time to arrange. Talk to your lead maternity carer and the Baby Friendly co-ordinator at your hospital about this.

Breast Milk Banks

There is only one New Zealand hospital-run milk bank, which is in Christchurch. It provides breast milk only to babies in Christchurch Women's Hospital Neonatal Intensive Care Unit. There is no official or regulated breast milk bank in New Zealand for mothers with HIV to access breast milk for their babies.

There are unofficial breast milk sharing services on Facebook, such as Piripoho Aotearoa, Human Milk 4 Human Babies, and Mother Milk NZ. However, the milk has not been screened so mothers do this at their own risk.

CLOSING STATEMENT

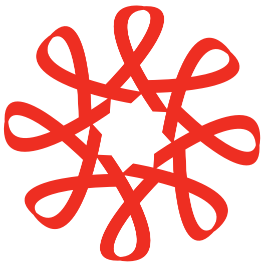
We hope you have found the information in this resource useful.

Remember, women living with HIV have the right to be supported to make informed decisions about pregnancy, birth and feeding their baby.

If you would like clarity about anything you have read or if you would like to connect with a woman living with HIV who has been through pregnancy, please contact Positive Women Inc. Contact details are on the back of this resource.

WOMEN LIVING WITH HIV HAVE OPTIONS AND CAN HAVE A HEALTHY BABY WHO IS HIV NEGATIVE.

NOTES



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www.apregistry.com

I-Base British HIV information site
www.i-base.info

New Zealand Fertility Plus
www.adhb.govt.nz/NWHealthInfo/gynaecologyServices/fertility_plus
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