TAC
TREATMENT ACTION CAMPAIGN

Pregnancy in our lives

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2010

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Contents

Severe illness or the death of a child is a tragedy for the family and for society. When that illness and death could have been avoided, we should get angry at our health services and politicians for not having provided the interventions to prevent it.

Furthermore, death or infection of a child from HIV is an indicator that women with HIV are not receiving the care and treatment they need for their own disease, as a child's health is directly linked to the health of his/her mother.

We saw a lot of deaths in the early part of this decade, before the PMTCT and antiretroviral programmes. Since the Department of Health has rolled out the programmes, people are living long and happy lives, with healthy children, usually born HIV–negative. This has been, in no small part, thanks to activists who tirelessly rallied against a government that didn't seem to take HIV seriously. Thankfully, this appears now to be in the past, with an energetic and committed health minister at the helm.

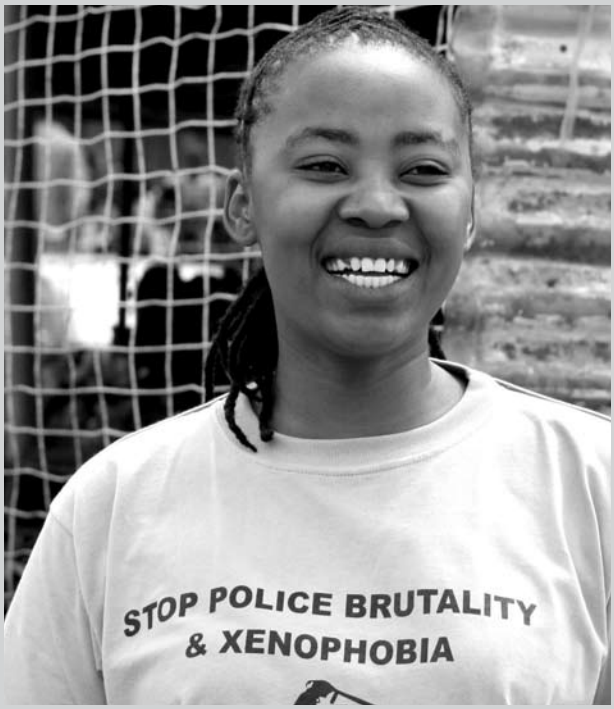
But, lots of work needs to be done. It doesn't matter if we have good guidelines, if we have the money in the budget, or that we have excellent and affordable generics, if the tablets don't find their way into the right mouths. The next struggle for all of us is to ensure that the health systems that provide care do so for as many people as possible. It is not good enough to have excellent ART and PMTCT coverage in key areas of Gauteng and the Western Cape, and not in rural Limpopo or urban Free State.

One of the best ways to get treatment to the right people is through patient empowerment. A senior professor at Wits specialising in rural health care was recently speaking at a conference. He said the difference between hypertensive and diabetic patients, and his HIV patient was incredible. "When you ask them what was wrong with them, the people with HIV could explain the life cycle of the virus, and how the drugs worked. When you asked the diabetic or hypertensive patients, they would shrug their shoulders and say they have 'the high-high'." Adherence in HIV programmes is more than 90 per cent, and coverage is improving, but it is much lower in other chronic illnesses, suggesting that education of people with HIV is critical to successful healthcare delivery. Knowledgeable communities can also fight locally for the correct treatments.

As usual, TAC and i-Base have produced an accessible and scientific handbook. We now need to get it out there, and ensure people with HIV demand and receive the care that they deserve and their right to health.

Professor Francois Venter

Notes to readers of this handbook



Hello, I am Vuyiseka Dubula. In 2001, at the young age of 22 years, I tested HIV-positive. At this time women living with HIV could easily be coerced to be sterilised and interventions to protect their unborn children were only available to a few.

We knew that programmes to prevent transmission of HIV to children could be an entry point to address sexual reproductive health and rights of women living with HIV. This led to women and men of the Treatment Action Campaign embarking on a PMTCT (prevention of mother-to-child transmission) campaign to represent the voices of many women who lived with HIV so that they could have a choice to have children free from HIV.

I took part in this struggle for access to HIV treatment. We all knew that our mission was that every person living with HIV should have access to HIV treatment as their constitutional right. But the question was how, in a country where HIV treatment was not considered a viable option for many poor people, although the state had a constitutional obligation to deliver healthcare services.

In the 1990s there were many studies that indicated that prevention of mother-to-child transmission programmes reduced infections and so we tactically chose to take up this campaign to force our government to see that antiretrovirals have a role in prevention and treatment. And to show that they, as the government, were the cause of many children being born HIV-positive even though they had evidence that there was something that they could do.

We had to take our government to court to force them to deliver on their promises by providing health services so that poor people could enjoy the right to life and dignity. We finally won the case in 2002.

Young women such as me enjoyed the outcomes of this case. When I finally decided I wanted to have a child, in 2004, I went to my doctor to seek advice and understand my options. The best option was for me to take HAART (highly active antiretroviral therapy)

because I needed to be healthy in order to have a healthy child. The doctor advised me that starting treatment early would reduce my viral load and increase my CD4 count, which was 269, so I began antiretrovirals in 2004. I planned to have my child in 2006. I took AZT, 3TC and nevirapine until I went into labour. My child also received nevirapine syrup after delivery and AZT for seven days after she was born. I am still on the same treatment regimen today. I did not stop. My baby was tested at six weeks and she was HIV-negative.

In December 2009 our president announced that South Africa would update its guidelines and implement the new revised World Health Organisation's guidelines. They would introduce early treatment for pregnant women, start treatment for people co-infected with HIV and TB when their CD4 count is less than 350 and treat infants immediately. This is commendable but our goal is that every person who has a CD4 count of 350 or less should be treated.

Introduction

The situation in South Africa

South Africa's prevention of mother-to-child transmission (PMTCT) programme has saved tens of thousands of children from dying of AIDS. It has also helped many pregnant women access life-saving antiretroviral (ARV) treatment to restore their health.

The programme has been particularly successful at primary healthcare level in Khayelitsha, Cape Town, where the mother-to-child transmission (MTCT) rate has fallen to below four per cent.

In one programme in Johannesburg, mothers receiving combination therapy, who need treatment for their own HIV, have a transmission rate of less than three per cent.

Yet, countrywide PMTCT remains poorly implemented. And in well-resourced countries mother-to-child transmission of HIV has been almost stopped completely. In the UK a mother receiving combination therapy, and whose viral load is undetectable, has a less than one in a thousand risk of transmission. So there is the potential to do even better!

But most women in South Africa do not receive the best treatment for their own health or the most effective PMTCT regimens (we will learn more about these in this handbook).

As a result, about 38,000 children are born with HIV in South Africa each year. A further 26,000 children are estimated to be infected through breastfeeding. More than six per cent of infants born each year in South Africa will become HIV-positive by their first birthday.

This means that deaths among children under five have increased. Death rates for pregnant women are also disturbing, having increased since 1997 due to the HIV epidemic.

Fortunately, this year things should begin to change. The government has launched a massive HIV Counselling and Testing (HCT) campaign aiming to get 15 million South Africans to voluntarily test for HIV by June 2011.

Our 2010 guidelines for HIV-positive pregnant women say that all women with CD4 counts of 350 cells/mm3 will be eligible for treatment, and that PMTCT prophylaxis should start earlier for women not yet eligible for treatment.

Our government must implement these improvements, greatly increase coverage and focus on the mother's own health to reverse previous trends.

How to use this handbook

This handbook can help you get the most out of your own HIV treatment and care if you are considering pregnancy, or during your pregnancy.

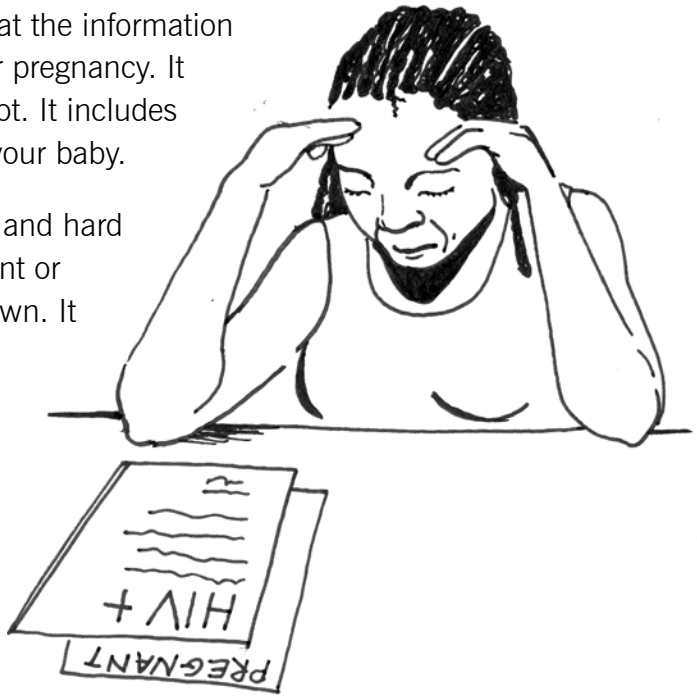
You may also be reading it because someone you know has found out that they are HIV-positive and pregnant. Or, you may be reading it because you are learning about HIV and pregnancy to help others, to train our community, and to advocate for better mothers' health and PMTCT programmes in South Africa.

Do not be put off if this information seems overwhelming at first and you cannot take it all in at once. You can read the handbook in sections. You can use it in your support group. You can use it for education in your treatment literacy workshops.

If more of us learn about HIV and pregnancy we can use our knowledge as a tool to support our health system to deliver good care and treatment. We can use it to demand the best care and treatment from our government. The more we understand about HIV and pregnancy, the more we can do to ensure the good health of mothers and babies in South Africa.

We have also included a section on planning pregnancy at the end of the handbook, as this is also of great importance to ensuring a woman's right to health.

If you have just been diagnosed with HIV in pregnancy



If you are using this handbook for yourself, we hope that the information here will be useful at all stages before, during and after pregnancy. It should help whether you are already on treatment or not. It includes information for your own health, and for the health of your baby.

You may be reading this handbook at a very confusing and hard time in your life. Finding out either that you are pregnant or that you are HIV-positive can be overwhelming on its own. It can be even more difficult if you find out both at the same time.

Before reading this handbook, you may never have known or read anything about HIV.

Pregnancy and HIV involve many new words and terms. We try our best to be clear about what these terms mean and how they might affect your life.

On an optimistic note, it is likely that no matter how difficult things seem now, they will get better and easier. It is very important and reassuring to understand the great progress made in treating HIV. This is especially true for treatment in pregnancy.

When you are HIV-positive and pregnant, the advice that you receive may be different from that given to other pregnant women. This includes information about medicines and breastfeeding.

Most people with HIV have a lot of time to come to terms with their diagnosis before deciding about treatment. This may not be the case if you are diagnosed during your pregnancy. You may need to make some decisions more quickly.

Whatever you decide to do is your choice but make sure that you understand the advice. Here are some tips if you are confused or concerned as you learn about HIV and pregnancy:

- Ask lots of questions;
- Take your partner or a friend with you to your appointments; and
- Try to talk to other women who have been in your situation.

The decisions that you make about your pregnancy are very personal. Having as much information as possible will help you make informed choices and to work with your healthcare team.

Background and general questions

Can HIV-positive women safely become mothers?

Yes! But with anti-HIV drugs. Women around the world have safely used these drugs in pregnancy for over ten years. Currently this usually involves a mother's treatment with three anti-HIV drugs, a strategy called combination therapy or HAART. The other method is to provide anti-HIV medicine to the mother to protect her unborn child. This strategy is called prevention of mother-to-child transmission or PMTCT.

Combination therapy or highly active antiretroviral therapy (HAART), are terms used to describe a strategy of using three or more antiretroviral drugs to treat HIV.

In South Africa we usually call anti-HIV drugs ARVs.

ARVs are not usually effective for treating HIV if only used one-at-a-time (this is known as monotherapy), but they can be very effective in combination with other medication.

For more information about ARVs, see *ARVs in our lives*.

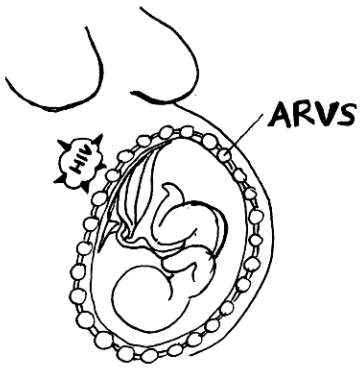
These anti-HIV drugs (antiretrovirals or ARVs) have completely changed the lives of people with HIV in every country where they are used.

Treatment has had an enormous effect on the health of HIV-positive mothers and their children. It has encouraged many women to think about having children or having more children.

Transmission of HIV is when the virus passes from one person to another. When this is from mother to baby it is called mother-to-child-transmission (MTCT), perinatal or vertical transmission.

Children who become HIV-positive in this way are called vertically infected children.

Your HIV treatment will protect your baby



The benefits of treatment are not just to your own health. Treating your own HIV will reduce the risk of your baby becoming HIV-positive to almost zero. Without treatment or prophylaxis, about 30 per cent of babies born to HIV-positive women in South Africa will be born HIV-positive. One in three is not good odds, though, especially because HIV drugs can almost completely prevent transmission.

How is HIV transmitted to a baby?

The exact way that transmission from mother to baby happens is still unknown. However, the majority of transmissions occur near the time of, or during, labour and delivery when the baby is being born. It can also occur through breastfeeding. We look at mother-to-child transmission and what we know about it on pages 11–14.

Certain risk factors seem to make transmission much more likely. The strongest of these is the extent of the mother's viral load.

So, as with treatment for anyone with HIV, one important goal of taking ARVs is to reach an undetectable viral load. This is particularly important at the time of delivery.

We have learnt that the most important thing is looking after a mother's health.

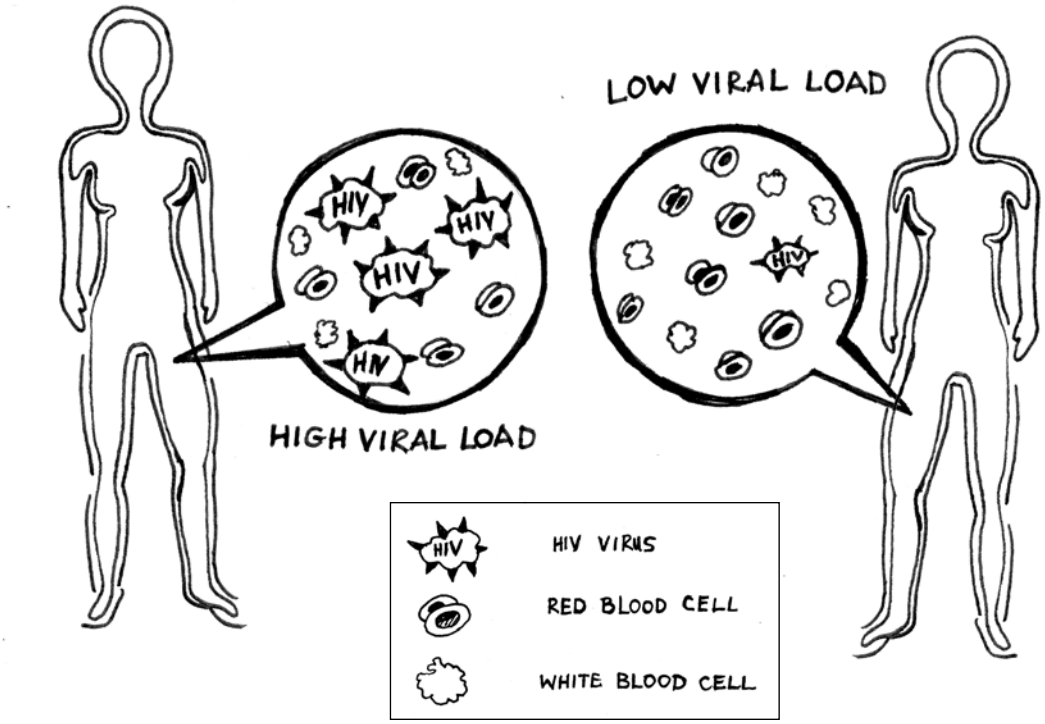
Some key points to remember:

- The mother's health directly relates to the HIV status of the baby;
- If the baby's father is HIV-positive it will not affect whether the baby is born HIV-positive or not; and
- The HIV status of your new baby does not relate to the status of your other children.

Viral load tests measure the amount of virus in your blood. The measurements are in copies per millilitre, for example 20,000 copies/ml (a ml is a tiny drop of blood).

Viral load is one measurement of the progression of HIV. The goal of treatment is to get your viral load to be undetectable to below 50 copies/ml.

If a mother's viral load is undetectable when her baby is born, the chance of mother-to-child transmission is close to zero.



Are pregnant women automatically offered HIV testing?

In South Africa, healthcare providers are required to offer all pregnant women who do not know their status an HIV test at their first antenatal visit.

If a woman chooses not to be tested, she will be counselled to help her look at her reasons for not testing and be encouraged to reconsider her decision. If she is still not ready, she will be offered HIV testing at every subsequent antenatal visit.

All women who test positive should have their HIV status confirmed using a second rapid test. If this is also positive, she should have a CD4 test, be screened for TB and be clinically staged according to the WHO staging system.

Women who test negative should be offered a repeat test from 32 weeks into their pregnancy, in case they contracted HIV during their pregnancy.

All this should now be part of routine antenatal care.

It is important for a woman to have an HIV test when she is pregnant. Her ability to look after her own treatment, health and well-being is improved when she knows if she has HIV or not. It will also help her protect her baby from HIV if she tests positive.

Women should receive optimal treatment for HIV – regardless of whether or not they are pregnant.

What should I expect when I have an HIV test during my pregnancy?

At your first antenatal visit you will have blood taken for routine antenatal screening, for example to check if you have any infections like syphilis, and to test your haemoglobin levels (red blood cells which transport oxygen around our bodies and contain iron).

Unless you decide against it, you will also have a rapid HIV test using a drop of blood from the sample taken or from a finger prick. Rapid (or point of care) HIV tests are just like traditional HIV tests that screen for the HIV antibodies and not the virus. The results are available within five to 30 minutes, which means that you can have pre-and post-test counselling, the test results, follow-up tests and any referrals all in one visit.

If the rapid test is positive, you will have another rapid test using blood from a second finger prick. If this test is also positive you have HIV.

If the second test is negative you will have a blood sample sent to a laboratory so that they can do an ELISA (Enzyme–linked immunosorbent assay) test. These results will take about a week.

If you have a positive HIV diagnosis, your CD4 test and TB screening should follow at the same visit.

Nurses and community health workers will be trained to do the rapid tests.

Do HIV drugs really protect the baby?

Mother-to-child transmission of HIV has just about been stopped in industialised countries. This is due to using more antiretroviral drugs in better combinations.

The reduction of mother-to-child transmission was an early benefit of antiretrovirals. PACTG 076 is the name of a trial completed in 1994. This was the first to show that the antiretroviral drug AZT could protect a baby from infection. HIV-positive mothers took AZT before and during labour, and the baby received AZT for six weeks after birth. This reduced the risk of the baby becoming HIV-positive from 25 to eight per cent.

After these results, this strategy was recommended for all HIV-positive pregnant women in several industrialised countries. Since then, even further advances have been made, particularly since combination therapy of three or more drugs became more common in the late 1990s. Transmission rates with combination therapy are now less than one per cent, practically down to zero.

What about poor countries?

A Ugandan study completed in 1999 showed that a single drug regimen was almost as effective as PACTG 076, but much simpler.

The HIVNET 012 trial in Uganda showed that a single dose of nevirapine given to an HIV-positive mother at the start of labour, followed by a single dose to her baby could reduce transmission by almost half. Similar results were shown in a South African trial called SAINT.

Single dose nevirapine was then recommended for MTCT in many developing countries including South Africa. It has provided an essential starting point from which to build MTCT programmes, train healthcare workers and begin access to antiretroviral treatment.

But I've heard that there are better strategies than single dose nevirapine

A study in Thailand called PHPT-2 then showed that the addition of single dose nevirapine to AZT given from 28 weeks of pregnancy further reduced MTCT from six per cent (with AZT alone) to two per cent.

Using AZT and single dose nevirapine together is now recommended in our 2010 PMTCT guidelines for pregnant women who do not require treatment for their own health.

In South Africa, women receive AZT from 14 weeks of pregnancy as this is considered more effective in preventing transmission than starting at 28 weeks.

Is it really safe to take HIV medicines during pregnancy?

Pregnant women are usually advised not to take any medication. This is not the case with HIV medicines during pregnancy. This difference can seem confusing.

No one can tell you that it is completely safe to use HIV drugs while you are pregnant. Some HIV medicines, for instance, should not be used during that period. However, many thousands of women have taken antiretrovirals during pregnancy without any complications to their babies. This has resulted in many babies being born HIV-negative.

Will being pregnant make my HIV worse?

Pregnancy does not make a woman's HIV any worse. It will not make HIV progress any faster.

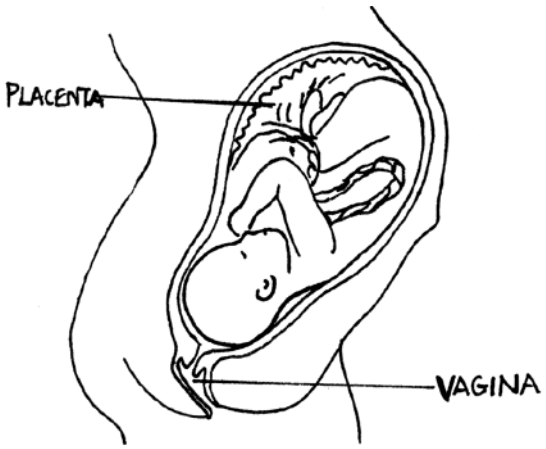
But, being pregnant may cause a drop in your CD4 count. It usually drops to about 50 cells/mm^3, but it can vary a lot. This drop is only temporary, and is due to your body increasing the amount of blood production, in anticipation of the birth. Your CD4 count will generally return to your pre-pregnancy level soon after the baby is born.

The drop is a concern, however, if your CD4 falls below 200 cells/mm^3. Below this level, you are at a higher risk from opportunistic infections (OIs). These infections could affect both you and

CD4 count and CD4 cells

- CD4 cells are white blood cells that help our bodies fight infection. These cells are also the ones that HIV infects and uses to make copies of itself to spread further.
- Your CD4 count is the number of CD4 cells in one cubic millimetre (mm^3) of blood. Your CD4 count is one measurement of the stage of your HIV.
- CD4 counts vary from person to person, but an HIV-negative adult would expect to have a CD4 count within the range of 400–1,400 cells/mm^3. Some factors, such as being tired, ill or pregnant, can cause temporary drops in a person's CD4 count.
- A CD4 count below 350 cells/mm^3 is considered low and treatment guidelines recommend starting treatment at that level or below. You are more vulnerable to infection if you have a CD4 count of below 200 cells/mm^3.

Prenatal refers to the period before a baby's birth; the time in which the foetus, or developing baby, grows in the uterus.



Opportunistic infections are infections that can cause serious illnesses in people with low CD4 counts. This often happens with HIV-positive people. OIs usually do not occur in people with healthy immune systems. OIs are less likely in people using ARVs.

the baby, and you will need to be treated for them immediately. In general, pregnant women need the same treatment to prevent opportunistic infections as everybody else.

Also, if you start taking treatment 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.

HIV does not affect the course of pregnancy in women who are receiving treatment. The virus also does not affect the health of the baby during pregnancy, unless the mother develops an OI.

Protecting and ensuring a mother's health

Your health and treatment are the most important things to consider to ensure a healthy baby. This is really important!

Sometimes medical research can forget the fact that HIV-positive pregnant women are people who need care for their own HIV. This can sometimes be neglected or forgotten by mothers and health workers when the baby's health is the main focus. Don't forget this. Your health and care are very important!

Overall, your treatment should be largely the same as if you were not pregnant. Circumstances where this is not the case will be mentioned later on in this handbook.

Prevention of transmission and the health of your baby have a direct link to your own care. Prenatal counselling for HIV-positive women should always include:

- advice and discussion about how to prevent mother-to-child transmission;
- information about treating the mother's own HIV now; and
- information about treating the mother's HIV in the future.

Your child is certainly going to want you to be well and healthy as he or she grows up. And, you will want to be able to watch him or her go to school and become an adult.

Basic principles of care:

- Health workers should provide information, education and counselling that is impartial, supportive and non-judgemental.
- HIV should be carefully monitored during pregnancy. This is particularly important the closer you get to giving birth.
- Opportunistic and other infections should be treated appropriately.
- Anti-HIV drugs should be used to reduce viral load to undetectable levels.
- Mothers should be treated in the best way to protect them from developing resistance to HIV drugs.

Nothing is more important to a child than the health of their mother.

Mother-to-child transmission

Despite remarkable achievements in reducing mother-to-child transmission, we do not understand fully how it happens.

This can be one of the hardest things to explain when we do our training workshops.

What we do understand, though, is that there are many factors that affect transmission. Of these, the extent of the mother's viral load is the most important. We will look at all these factors in this section.

MTCT 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 AIDS illnesses 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.

But most transmissions happen during delivery 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 foetus.

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

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

The reason we know that in utero transmission happens is that a proportion of HIV-positive babies tested when they are a few days old already have detectable virus in their blood. The rapid progression of HIV disease in some babies has also made scientists conclude that this happens.

Having a high viral load, AIDS and a low CD4 count make in utero transmission more likely.

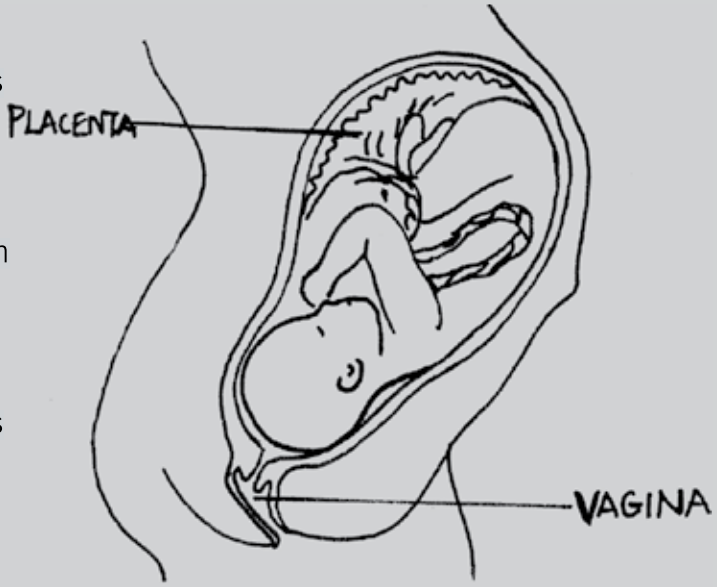
Having TB at the same time also makes it more likely and HIV makes in utero transmission of TB more likely.

Malaria also increases the risk of HIV transmission.

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

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

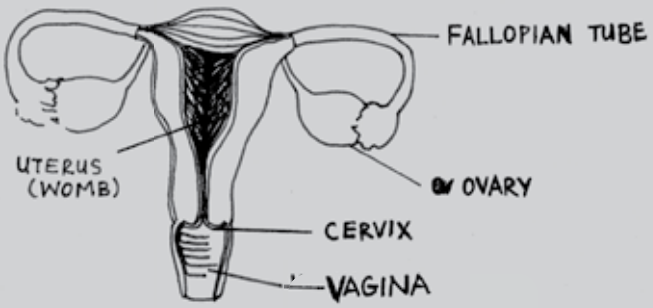
Placenta is a temporary organ that develops in pregnancy and joins the mother and foetus. The placenta acts as a filter. It transfers oxygen and nutrients from the mother to the foetus, and takes away carbon dioxide and waste products. The placenta is full of blood vessels. The placenta is expelled from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



Foetoplacental circulation is the blood supply in the foetus and placenta.

Foetal membranes are the membranes surrounding the foetus.

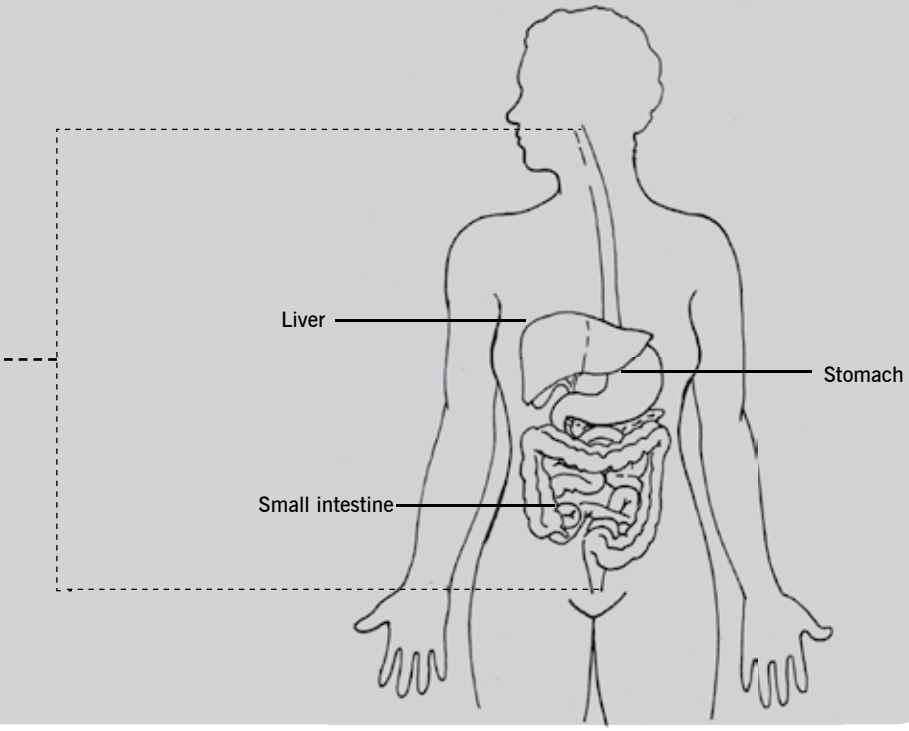
Maternal-foetal microtransfusions is when small amounts of infected blood from the mother leak from the placenta to the baby during labour (or other disruption of the placenta).



Chorioamnionitis is inflammation of the chorion and the amnion, the membranes that surround the foetus. 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, lungs and stomach). Glands in the mucosa make mucous, a thick, slippery fluid. Mucosal lining is also called the mucous membrane.

Gastrointestinal 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. It is sometimes called the GI tract.



During labour and delivery (intrapartum transmission)

Transmission during labour and delivery 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 foetal membranes and amniotic fluid, and through absorption in the digestive tract of the baby.

Alternatively, during contractions in labour, maternal-foetal microtransfusion may occur.

Scientists know that transmission occurs during delivery because:

- Fifty per cent of HIV-positive babies test HIV-negative in the first few days of life.
- 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.

It is also shown by the ways to prevent it happening. These include:

- Lowering the mother's viral load with ARVs; and
- Delivering the baby by Caesarean section before labour starts.

If it takes a long time for the membranes to rupture (waters breaking) and if there is a long labour, it can also increase the risk of transmission in women not receiving ARV treatment or prophylaxis.

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

Breastfeeding

Doctors think that HIV in breast milk 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 adults.

It is unclear whether damage to the intestinal tract of the baby, caused by the early introduction of other foods, particularly solid foods, could increase the risk of infection.

We look at breast- and formula feeding in our section on infant feeding on pages 36–41.

The most important thing to know about MTCT is not how it happens, but how we can prevent it from happening. We can do this with ARVs. Fortunately we know a lot more about that!

Pre-conception, planned pregnancy, and your right to have a baby

Many HIV-positive women become pregnant when they already know their HIV status. Many women are also already taking ARVs when they become pregnant.

If you already know that you are HIV-positive, you may have discussed the possibility of becoming pregnant as part of your routine HIV care.

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

- consider your general health;
- have appropriate check-ups; and
- treat any sexually transmitted infections.

You should also make sure you are receiving proper care and treatment for your HIV.

What to do when one partner is HIV-positive and the other is HIV-negative

There is still controversy over the best advice to give to couples who are sero-different or sero-discordant. These are terms used when one partner is HIV-positive and the other HIV-negative.

It is usually unwise for sero-different couples to have unsafe or unprotected sex without a condom.

There is always a risk, even if it is a very tiny one, to the HIV-negative partner of contracting HIV.

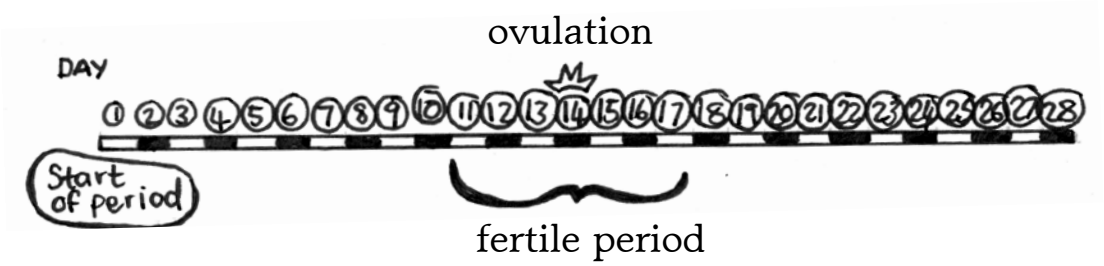
For an HIV-negative woman, the chance of becoming HIV-positive from having unprotected sex will depend on many things, including the viral load in the semen of her male partner. It is important to remember that an undetectable viral load result from a blood test does not mean that the viral load is undetectable in seminal fluid.

For an HIV-negative man, transmission risk depends on the level of viral load in the genital fluid of his female partner. Again, an undetectable viral load in blood does not always mean the same as in genital fluid.

Other factors are also important. An uncircumcised man is likely to be more at risk of contracting HIV because cells in the foreskin are more vulnerable to infection. And, having sex with an uncircumcised, HIV-positive man may be of greater risk to an HIV-negative woman than sex with an HIV-positive circumcised man.

Infections of the genital tract also increase the risk of sexual transmission of HIV. Regardless of the method of conception (we look at these methods later), both members of a sero-different couple should check for such infections. This should include screening and treatment for other sexually transmitted infections.

All these risk factors aside, HIV is actually quite a difficult virus to transmit. Statistically it is much harder to transmit HIV than to get pregnant. Therefore, limited conception attempts made during ovulation, a woman's fertile period, may carry a low risk if the positive partner has undetectable levels of viral load. But, there is still a risk for negative male and female partners from any single unprotected exposure. After all, people can conceive from one attempt, and also become HIV-positive from one exposure.



In one study of HIV-negative women and HIV-positive men, four per cent of women became HIV-positive but this study took place before the routine use of HAART.

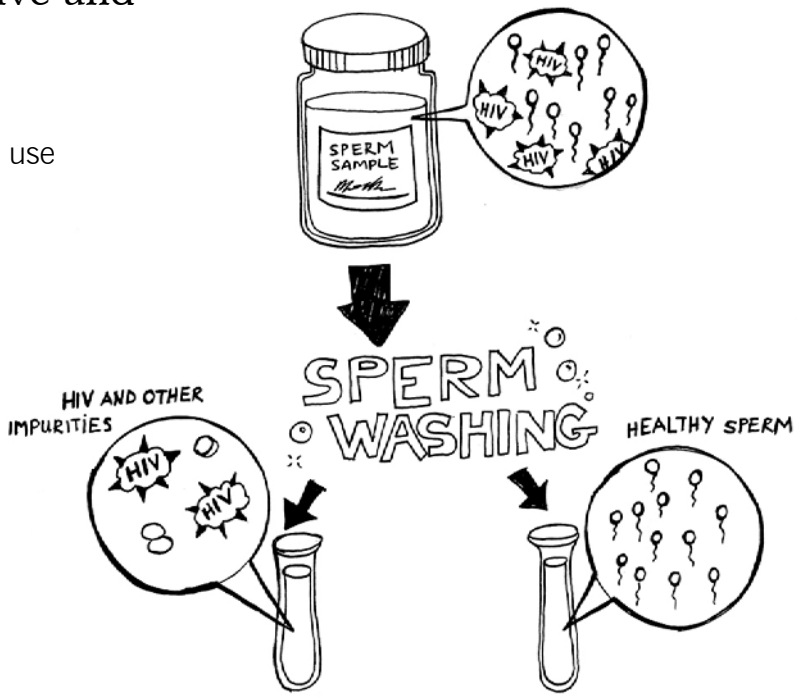
Here's something important to think about. Although a low number of conception attempts can be relatively safe, some couples do not return to safer sex afterwards. This often results in the negative partner then becoming HIV-positive. HIV is a disease that affects the rest of your life. If one of you has stayed HIV-negative until now, you don't want to change this over a decision to have a baby.

For those who wish to conceive, the options are discussed below.

When the man is HIV-positive and the woman HIV-negative

When the man is HIV-positive and the woman is HIV-negative, it is possible to use a process called sperm washing.

This involves the man giving a semen sample to a clinic. A special machine then spins this sample to separate the sperm cells from the seminal fluid. Only the seminal fluid contains HIV-infected white blood cells; sperm cells themselves do not contain infectious HIV.



The washed sperm is then tested for HIV. Finally, a catheter is used to inject the sperm into the woman's uterus. In vitro fertilisation (IVF) may also be used, especially if the man has a low sperm count.

There have been no cases of HIV transmission to women from sperm washing.

This method is not available in the South African public sector though and is very expensive. It also does not always have a very good success rate.

Andile Madondile

I was invited by the Siyaqoba Beat Programme in 2006 to take part in their research on how sperm washing could be done and how much it costs. We visited a private gynaecologist in Wynberg because I wanted a child as I had recently married. My wife is HIV-negative and I am HIV-positive (sero-discordant partners).

Luckily I was given a donation by a Swedish journalist because my wife and I really wanted to have a child. She was really afraid of being infected with HIV if she was to become pregnant. I had to do a lot of tests before they decided that I was eligible.

They looked for things like STIs, an undetectable viral load, a CD4 count of 400, no drug or alcohol abuse, no cancer in my testicles, and needed to know what medication I was taking and any drug allergies I might have. My wife also had to undergo tests.

They took a sperm sample from me and put it through a machine to separate the semen and injected the sperm into my partner. It was a learning process for me.

Some of the problems my wife and I experienced during this procedure was because of the cultural differences between us and the hospital staff. For example, as a black man I was uncomfortable talking to a female nurse about my private parts. My wife was uncomfortable opening her legs for a white man. This is not accepted practice in our culture but the treatment literacy I received at TAC and Siyaqoba assisted us.

My wife and I returned one month later to see if she was pregnant. She was and gave birth like any woman. We are blessed with a baby boy named Onako, who is two and a half years old now. He went for an HIV test just to make sure that he is not infected with HIV. My wife also still tests negative.

I believe that men who know they are living with HIV/AIDS have a responsibility to make sure that their partner stays negative. I always use condoms and take precautions. I am a proud father and playing with my son is one of my favourite pastimes.

The Swiss Statement

The "Swiss Statement" was issued in January 2008 by the Swiss Federal Commission on AIDS Related Issues (an expert group of doctors and researchers). This group was concerned about the legal situation to HIV-positive people in Switzerland and for sero-different couples who wanted to have a baby.

They were worried about the accuracy of public and private information about the risk of HIV transmission for people on antiretroviral treatment.

One of the reasons that they issued the statement was to give doctors guidance to help sero-discordant couples wishing to conceive a child. Many couples are unable or unwilling to use sperm washing or other methods of assisted reproduction and need to be able to make informed decisions about the level of risk involved with having sex when using antiretrovirals.

The statement described the transmission risk for someone on stable therapy as "negligible" and "similar to risks of daily life".

It explains that, for example, even condom use is not 100% safe.

The statement makes it very clear that this description of someone at a very low risk of transmission only applies to someone who:

- Has an undetectable viral load for at least six months;
- Has excellent adherence; and
- Has no other STIs.

The Swiss doctors calculated that conceiving naturally under these circumstances would be unlikely to lead to HIV infection in the HIV-negative partner. They were not recommending that condoms should now be abandoned forever – just that the risks during limited conception attempts were so small compared to the importance for many couples to have children.

They also stated that PEP (post exposure prophylaxis) treatment wouldn't be given if a condom broke and the HIV-positive partner fulfilled the above criteria.

If you want to read more about the Swiss Statement: http://www.aids.ch/e/fragen/pdf/swissguidelinesART.pdf

As we mentioned earlier, a more controversial option is to have limited conception attempts during the most fertile days in a woman's cycle. To make this safer, an HIV-positive man must use HIV treatment to reduce his viral load to undetectable levels in both his blood and semen. Conception can either be natural or with self-insemination. If you decide to have intercourse, the sex needs to be gentle to ensure no tissue damage, as this can increase the chances of HIV transmission. Health workers can provide guidance on how to plan and identify which days are your most fertile.

Viral load in semen can be tested using the same viral load tests that are used for blood, and your clinic could advise on this.

Approximately ten per cent of men with undetectable levels of HIV in their blood can have detectable levels in semen.

Artificial or self-insemination (see next page) would reduce the risk of trauma during sex where a small tear could increase the risk of HIV transmission.

Continuing to use condoms at all other times is essential.

Having sex or self-insemination is more controversial because there is still a small risk of transmitting HIV. However, especially where spermwashing is not available, there have been encouraging reports that this has been successful. In one report, around 60 couples conceived without any HIV transmission. For many women who want to have children, this risk may be acceptable, but it must be something that she decides to do herself and is not pressurised into.

If you do decide to do this, there may be an additional safety benefit to the woman by using HIV-drugs for one or two days to reduce the slight chance of infection even further. Several studies are looking at whether using tenofovir and FTC (or 3TC) before exposure to HIV is protective.

When the woman is HIV-positive and the man is HIV-negative

The options are usually much simpler in this situation. Do-it-yourself artificial insemination or self-insemination using a plastic syringe carries no risk to the man. This is the safest way to protect the man from HIV.

Around the time of ovulation, you need to put the sperm of your partner as high as possible into your vagina. Ovulation takes place in the middle of your cycle, about 14 days after the start of your last period.

Different clinics may recommend different methods of collecting the sperm. One way is to have protected intercourse with a spermicidal-free condom. Another is for your partner to ejaculate into a container. In both cases, you then insert the sperm into your vagina with a syringe.

Your clinic can provide the container and syringe. They can also give detailed instructions on how to do this, including advice on timing the process to coincide with your ovulation.

When both partners are HIV-positive

For couples where both partners are HIV-positive, most doctors still recommend safer sex. This is to limit the possibility of re-infection with a different strain of HIV.

It is likely that this risk is very low, but it is possible. The risk of re-infection is even less likely if you only have unprotected sex a few times in order to conceive a baby.

Here are some other things to consider about the risk of re-infection:

- The risk between HIV-positive couples is also likely to relate to viral load levels;
- This risk is likely to be higher if one partner is doing well on treatment, while the other partner is untreated and/or has a high viral load; and
- The risk is more serious if one partner is resistant to HIV treatment.

If you routinely practise safer sex, you may be advised to limit unprotected sex to the fertile period. You could also follow the advice for sero-different couples.

For HIV-positive couples who do not practise safer sex, continuing to do so to conceive a baby will carry no additional risk.

All these options involve very personal decisions. Knowing and judging the level of risk is an individual decision.

All methods of becoming pregnant carry varying degrees of risk and success. Sperm washing and fertility treatment may be expensive and is something you need to think about.

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

Can I get help if I am having difficulty conceiving?

All couples can experience some fertility difficulties, regardless of who is HIV-positive or even if you both are.

There are things you can do, though, which have all had some success. But, sometimes they are not as easy as they sound.

If you have fertility problems, ask your doctor about assisted reproduction. Find out about the possibility of referral to a fertility clinic with experience of HIV.

Is fertility treatment available to HIV-positive people?

Yes. Fertility is as important when trying for a baby whether or not you are HIV-positive.

The same fertility support services should be provided for people who are HIV-positive as for HIV-negative people.

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 are HIV-positive. If you do, then you can and should complain.

You may want to choose a clinic that is more sympathetic, or perhaps a clinic that has more experience with HIV-positive parents.

Antenatal care and HIV treatment

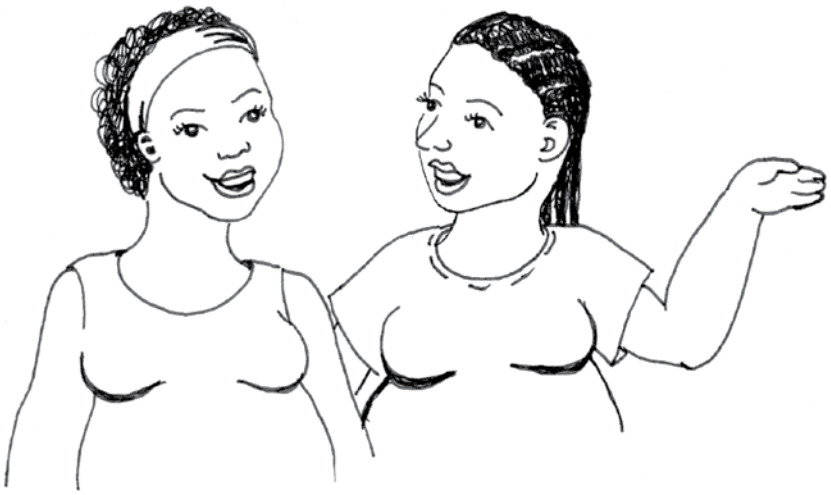
Antenatal care

Antenatal care is also called prenatal care. This covers all the extra healthcare that you receive during your pregnancy in preparation for your baby's birth.

Antenatal care is not only about medicine and tests. It also includes counselling and information, as well as advice on your general health such as exercising and stopping smoking.

As with all aspects of HIV care, it is very important that members of your healthcare team have had specialist experience with HIV-positive women.

It is also important that the people responsible for providing your care are up to date with the most recent developments in preventing mother-to-child transmission and HIV care.



Does every HIV-positive woman need to use ARVs in pregnancy?

Every pregnant woman with HIV should use ARVs in pregnancy. Even if you do not need treatment for your own HIV, you should still use ARVs to prevent transmission to the baby.

In the following section, we explain what you will need to do to at different stages of HIV.

What if I do not need treatment for my own HIV?

South African guidelines recommend starting HIV treatment when your CD4 count is below 350 cells/mm^3, or at WHO stage 3 or 4.

Women who do not need treatment for their own health will receive a PMTCT regimen to reduce their viral load and the risk of HIV transmission to the baby.

In South Africa you will be given AZT from 14 weeks of pregnancy, a single dose of nevirapine (NVP) at the beginning of labour, AZT every three hours during labour, and a single dose of tenofovir (TDF) and emtracitabine (FTC), often as a combined tablet, during labour.

Nomawethu Ndindwa

I am Nomawethu Ndindwa. I live in Lower Ntafufu, or Tambo, Lusikisiki.

I was diagnosed HIV-positive during my pregnancy in 2001. At the hospital they didn't tell me what blood tests they were doing. My child died when he was a year and one month on 23 February 2002. He was never tested.

In 2005 I was pregnant again, this time with twins. At five months pregnant I did a CD4 test and my count was 247. This time I started ARVs, took AZT, 3TC and NVP.

My twins were given NVP syrup at birth. They are both negative. I am still taking my ARVs and I adhere to them. I haven't experienced any side effects.

Neliswa Nkwali

Hello. I am Neliswa Nkwali. My hometown is Butterworth, Eastern Cape.

I was diagnosed HIV-positive on 8 October 2001. In 2003, I became ill with pulmonary TB. I took TB medication and I started ART on 1 April 2003, when my CD4 count was 39. I was very sick.

I told my family that I was beginning ART and they were supportive, especially my youngest brother. Although some people told me that ART was dangerous, comrades at TAC encouraged me to take the drugs. I first took AZT, 3TC and efavirenz. My CD4 count started to rise and I began to feel better. I felt that I had been given a new opportunity in life and I felt happy again.

In 2004 I decided I wanted to get pregnant. My CD4 count was 439. Comrades at TAC had told me that it was possible for me to have an HIV-negative baby, especially if I continued ART. Before I got pregnant I took advice from the doctor and switched from efavirenz to nevirapine. When I discovered I was pregnant, I cried with happiness.

Some people in my community were critical of me when they found out that I was pregnant. They knew that I had been very sick with AIDS a few years ago and didn't understand about ARVs and PMTCT. My family was supportive of me but they were also very worried that my baby would be born HIV-positive. My doctor and nurses were very helpful though.

I tried to avoid stress during pregnancy and ate healthily. I also made sure that I adhered to my schedule, always taking my drugs at the right times. My CD4 count went down to 329 but I knew that this was common in pregnancy. My CD4 count recovered after my baby was born and continues to rise. Currently my CD4 count is 889.

My baby, Siviwe, was born on 15 June 2005 by vaginal birth. He is HIV-negative. He is very active, energetic and brilliant. I try to keep him close to me as I love him so much.

The message I want to send to HIV-positive women is to look after your health, plan your pregnancy and learn all you can about HIV and pregnancy. Talk to your doctor and nurses and consider your viral load. Your own health is the best way to ensure a healthy baby. And you want to be around to see him or her grow up!

What if I'm HIV-positive and need treatment for my own HIV?

You may only find out that you are HIV-positive when you are already pregnant. This can be a very difficult time practically and emotionally. Ask for extra support if you need it.

If you are diagnosed in pregnancy and need to start treatment, you are most likely to receive NVP, TDF, 3TC or FTC, which can be started at any time during pregnancy.

You will be "fast-tracked" to start treatment as soon as possible after you are found to be eligible.

If you have renal disease (meaning your kidneys do not function well), you will receive AZT and 3TC because TDF may be harmful to people who have kidney problems.

What if I discover I am HIV-positive when I am in labour?

If you test HIV-positive in labour you can still benefit from using antiretrovirals. You will receive a single dose of nevirapine, plus TDF and FTC, plus AZT at the beginning of labour and then on a three hourly basis until the baby is delivered.

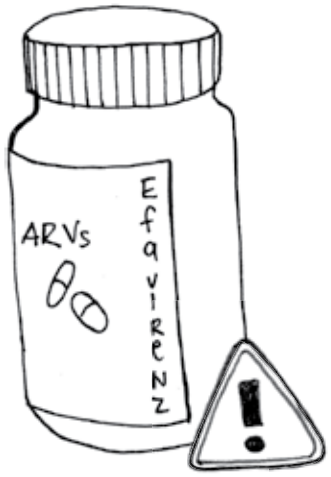
What if I am already using HIV treatment when I become pregnant?

Many women decide to have a baby when they are already on treatment. This speaks volumes about the tremendous advances made with HIV drugs.

Women feel better. They are healthier and start thinking about long-term relationships. They are thinking about the future and the possibility of 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.



Drugs not recommended in pregnancy

Efavirenz is not recommended during pregnancy in South Africa.

This is because, in a single pre-clinical animal drug trial, this drug caused neural tube defects or brain damage in the developing foetus.

Because many pregnancies are unplanned, there are many reports of women who have conceived while receiving efavirenz and so far it does not seem to show an increased risk of birth defects to human babies.

Some doctors therefore think that using efavirenz is just as safe as taking any other ARV in pregnancy.

If you find out that you are pregnant before 12 weeks and are using efavirenz, you will be switched to nevirapine.

If you are already 12 or more weeks pregnant when you find out and have been taking efavirenz during this time, don't panic! You will need a test called the maternal alpha fetoprotein test. This is a screening test for neural tube defects.

It is highly unlikely that your baby will be affected.

It is possible to use most second line HIV drugs in pregnancy.

Should I expect more side effects when I am pregnant?

Many pregnant women using HAART will experience some sort of side effect with these drugs. This is similar to people using HIV treatment who are not pregnant.

Most side effects are minor and include nausea, 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 HIV medicines are very similar to the changes in your body during pregnancy, such as morning sickness. This can make it harder to tell whether the treatment or pregnancy is the cause.

HIV medication can cause nausea and vomiting. This is more common when you first begin taking them. If you are pregnant, though, such side effects can present extra problems with morning sickness and adherence.

You may feel more tired than usual. Again, this is to be expected, especially if you are starting HIV treatment and are pregnant at the same time.

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 appears to be particularly risky for lactic acidosis.

Nevirapine can cause a rash. If you get a rash with nevirapine, you should make sure your health worker checks this carefully.

Approximately five per cent of people discontinue nevirapine due to a rash.

Anything more than a mild rash may require you to stop taking nevirapine – but only on the advice of your health worker.

More serious rash (reported in 0.5 per cent of cases) can be life-threatening (Stevens-Johnson Syndrome) and can be dependent on how early nevirapine is discontinued. This is why getting an expert medical assessment when a rash appears is essential.

Nevirapine can also cause problems with the liver.

When you first start taking nevirapine you will receive a lower dose (200mg once daily) for the first two weeks and this will increase to 200mg twice daily. This is because nevirapine levels are highest in the first two weeks so you are more at risk from side effects.

During this first eight weeks you should contact your clinic straight away if you have any of the following symptoms:

- Rash;
- Blistering of the skin (seek immediate medical attention);
- Mouth sores;
- Facial or general swelling;
- Fever; and
- Flu-like symptoms, aching muscles or joint pains.

Tenofovir is not recommended for people with reduced kidney function. You will have this checked before you start tenofovir, particularly if you weigh less than 50kg.

Anaemia (low red blood cells) can cause fatigue. It is a very common side effect of both AZT and pregnancy. It is also very common in people with low CD4 counts. A simple blood test can check for this. If you have anaemia, you may need to take iron supplements but consult your doctor or clinic first.

Safety data means that a drug has been used safely in a certain number of people. Generally, the more information we have on the use of a drug in a large number of people, the more confident we can be that it is safe to use in the population.

Pre-clinical testing: before any drugs are tested on humans, they will be tested in the laboratory and on animals. This will not always show what will happen when people use the drugs, but it can provide a guide to serious problems that could occur.

Resistance, monitoring and other tests

What about resistance?

Drug resistance is an important issue during pregnancy. Some strategies to reduce mother-to-child transmission can also easily lead to resistance.

Resistance

Resistance to drugs occurs when the structure of a virus makes tiny changes that stop the drug from working. These changes are called mutations.

- If you just take one drug or a combination of drugs that are not strong enough to get your viral load down to an undetectable level, then HIV can become resistant to the drugs.
- If you are resistant to a drug it will no longer work as well, or it may not work at all.
- To avoid resistance, you need to take a combination of at least three antiretroviral drugs. There are now new ways to protect you from resistance with PMTCT strategies.
- It is important to avoid resistance in pregnancy.

Using single dose NVP alone or with AZT can lead to resistance in both mothers and babies.

This is because NVP stays in our bodies for some time, giving the virus the opportunity to make changes to stop NVP working against it. NVP also only needs a small change in the virus to cause resistance.

To help prevent this, South African guidelines recommend using a single dose of TDF and FTC during labour. This strategy is sometimes known as “covering the tail”.

Resistance can also occur if you are already using combination therapy and your viral load is not undetectable. It is important that, together with your health workers, you look at why this is happening. This is very important for your own and your baby’s health.

Resistance can develop when your viral load is detectable. This will affect your long-term health. Viral load at the time of delivery is also strongly linked with risk of transmission to your baby.

It is also possible to transmit a resistant virus. A baby born with drug-resistant HIV is much harder to treat.

Monitoring for opportunistic infections and other tests and care

Treatment and prophylaxis for most OIs during pregnancy are very similar to that for non-pregnant adults. Only a few drugs are not recommended.

Your healthcare provider should check for OIs as part of your ongoing HIV care. You may need to be treated for other infections, especially if you are diagnosed with HIV during pregnancy.

You are particularly vulnerable if your CD4 count is less than 200 cells/mm^3. You should also be provided with cotrimoxazole prophylaxis. If your CD4 count is less than 350 you will need to start ARVs urgently.

Prophylaxis against cytomegalovirus (CMV), candida infections and invasive fungal infections is not routinely recommended. Treatment of very serious infections should not be avoided because of pregnancy.

Your clinic should give you a thorough gynaecological check up. Otherwise tests will be fairly routine, and may vary slightly from doctor to doctor. Routine tests include checking blood pressure, weight, blood and urine.

HIV and TB

It is important to treat TB in pregnancy. HIV/TB co-infection increases the risk of mother-to-child transmission of both infections. TB can also increase the risk of the less common in utero mother-to-child transmission of HIV. This is when HIV transmission takes place in the womb rather than during labour.

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

You will be screened for TB at your first antenatal visit.

Most first-line TB drugs are safe to use in pregnancy. The TB drug, streptomycin, is not recommended in pregnancy as it can cause permanent deafness in the baby, but is only used in situations where you are re-treated for TB or have TB drug resistance. TB nurses are trained in how to use these drugs in pregnancy, so it is very important to tell the nurse that you are pregnant if you are on TB treatment.

Some second line TB drugs are not usually recommended in pregnancy. If you need to use second line TB drugs in pregnancy you will need to be treated by a specialist in treating TB and HIV, who can work out which TB drugs are best for your circumstances. Again, your own health is most important.

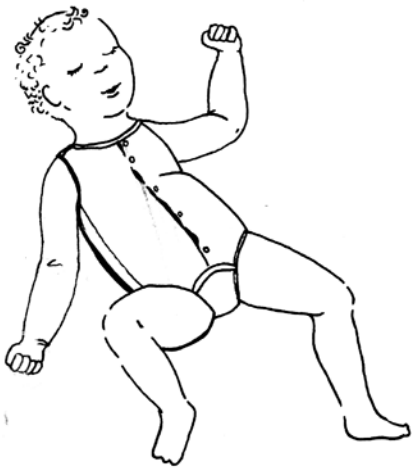
In general, you should always try to complete your TB treatment before falling pregnant, to decrease the problems we see with some of the TB drugs.

Isoniazid preventative therapy (IPT) is safe to use in pregnancy.

(See our publication, *TB in our lives,* for more information about TB and treatment).

HIV drugs and the baby's health

Some mothers and doctors have been reluctant to use or to prescribe anti-HIV drugs during pregnancy. This is out of concern for the unknown effects to the baby.



Unfortunately, it is difficult to know if there are any long-term side effects. Today, even children who were first exposed to AZT alone during their mothers' pregnancy are not older than teenagers. Children first exposed to combination therapy are not likely to be much older than ten.

Careful follow-up of children exposed to AZT has not shown any differences compared to other children.

As more children are born to HIV-positive women all over the world, we will have more important safety information for women and children in the future.

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

Will HIV drugs affect the baby?

These concerns are justifiable. Unfortunately, there are no definite answers, although overall the drugs do seem reasonably safe.

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

Prematurity

Several studies show a greater risk of prematurity (babies born at less than 37 weeks) and low birth weight for babies born to mothers taking anti-HIV treatment of three or more drugs. Other studies show no risk.

A British study found an overall rate of 13 per cent, while normally the rate in Britain is about six to eight per cent.

This should not be a reason for a mother to avoid treatment in pregnancy, particularly if she needs it for her own health. It is, however, important to be aware of the risks. Discuss them with your healthcare team and make sure that you are receiving the best possible treatment, care and monitoring for yourself and your baby in your situation.

Can anti-HIV drugs cause birth defects?

There have been very few reports of birth defects in babies whose mothers have taken ARVs during pregnancy. So it is not possible to say whether these are related to ARVs or not.

What about anaemia?

Anaemia has been reported in babies born to mothers on HIV medication, but this passes quickly and infants can be treated with iron and multivitamin supplements or, more rarely, they may require a transfusion.

Prophylaxis is when you take a drug to prevent an infection or re-infection before it occurs.

Delivery

A Caesarean section is a procedure to deliver a baby that involves making a cut through the abdominal wall to surgically remove the infant from the uterus.

In South Africa, most mothers with HIV will have their babies by vaginal delivery unless there are particular complications.

Caesarean section

If you do have a Caesarean section, and it is planned, the operation must be carried out before the onset of labour and before membranes begin to rupture. This is called pre-labour, elective or scheduled Caesarean section. With an elective Caesarean section, you should receive antiretroviral prophylaxis of single dose NVP, TDF and FTC and the AZT started four hours before the Caesarean. If it is an emergency Caesarean you should also receive these drugs before the procedure.

Occasionally women have to have emergency Caesarean sections when they are already in labour.

If you have your baby in the private sector, you may be offered the option of an elective Caesarean section as part of PMTCT.

Should I have a pre-labour Caesarean section if it is offered?

If a woman's viral load is undetectable on combination therapy, the risk of transmission associated with either mode of delivery is so low that it is impossible to say which carries the lowest risk of transmission.

There is also no benefit to having a Caesarean section if your waters break before the operation.

Will a Caesarean section stop me having a natural birth in the future?

This is a very important consideration. If you have a Caesarean section now, having a natural birth in the future is more difficult. You may be offered the choice of vaginal delivery, but you will more than likely end up needing a Caesarean section. Once a woman has given birth by Caesarean section it is usually recommended that she has a Caesarean for future babies.

Is there anything that I should remember for the birth?

If you are on HAART, it is very important that you remember to take all your drugs on time, as usual. This is a critically important time to make sure that you don't miss any doses. It can be difficult to remember to do this especially during labour, and particularly if your labour is long. Make sure that your partner or friend and healthcare team know your medication schedule and where you keep your medication. They can remind you to take your pills on time.

If you have your baby at home and not in a health facility, make sure that your birth attendant helps you with this.

After the baby is born

What will I need to consider for my own health?

Adherence! This means taking your drugs exactly as prescribed. If you are receiving combination therapy, your own adherence to your drug schedule 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 healthcare team. You may also find a community group very helpful.

Many mothers find that 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 of ARVs a day and you have two doses, make sure that they are taken at the same time.

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

Babies born to HIV-positive mothers will always test HIV-positive at first. This is because they have their mum's immune system and share her antibodies. If your baby is not infected with HIV, these antibodies will gradually disappear and he or she will be HIV-negative. This can, however, sometimes take as long as 18 months.

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

To have a PCR test, your health worker will take a sample of your baby's blood, either liquid or dried blood spots on a filter paper, when he or she is six weeks old.

If this test is negative and you are not breastfeeding your baby, then your baby is not HIV-positive.

If you are breastfeeding, the baby will need another PCR test in case the baby is infected through breastfeeding.

The baby will have a final HIV antibody test at 18 months old (ELISA) to confirm that he or she no longer has your antibodies. This is called sero-reversion.

Checking your child's HIV status

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.

ELISA

Enzyme-linked immunosorbent assay (ELISA). This test detects the presence of antibodies to HIV in our blood.

Busi Maqungo

When my boy was born in December 2002, there was no PCR test available then, so I had to wait for the ELISA test to check his status. That was the longest wait of my life – nine months felt like nine years. I understood that even though I took NVP it was never 100 per cent guaranteed that my child would be saved. Every little sickness made me panic and when the time finally came for him to go for a test, I refused. This was because I understood he could test positive even though he was negative. I was not ready for that. My other option was to go for a PCR test. At least this kind of test gives accurate results. My son was ten months old when I took him for the PCR test. He tested HIV-negative. He is now five years old and is healthy and energetic. His name is Luthando.

Will my baby need to take HIV drugs after he/she is born?

How long the baby needs to take these depends on what drugs you received during your pregnancy and will be on after delivery.

What the baby will need depends on what drugs you received during your pregnancy.

- If you started HAART during your pregnancy and are continuing lifelong, your baby will receive nevirapine at birth and then daily for six weeks whether you breastfeed or formula feed your child.
- If you received the PMTCT regimen, then your baby will receive NVP at birth and continue daily for as long as you are breastfeeding or for six weeks if you are formula feeding.
- If you did not receive any ARVs in pregnancy or during delivery, the baby will also receive NVP as soon as possible and daily until the end of the period of breastfeeding or six weeks if formula feeding. You will be assessed to see if you are eligible for HAART.

If you deliver your baby at home you will need to take your baby to the clinic as soon as possible.

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

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

We also have some information on contraception in this handbook on pages 43–46.

Infant feeding – risks and options

There are two ways to feed a new baby. Both have pros and cons. We will look at the pros and cons of breastfeeding and formula feeding in this section.

Vuyiseka Dubula

Before my daughter was born, I was advised to either exclusively breastfeed or exclusively formula feed for at least the first six months. I chose formula feeding for my child because I knew there was a higher risk of HIV transmission through breastfeeding. I knew that the chances of transmitting HIV to my child were minimal because I had an undetectable viral load, but I couldn't take a chance with my only child. I would not be able to live with myself if she was infected. Formula feeding requires more cleanliness. When I prepared the feed I had to sterilise the bottles, and I made sure I used boiled water all the time. I was also told about cup feeding, which carries less risk of exposure to bacteria than bottle feeding.

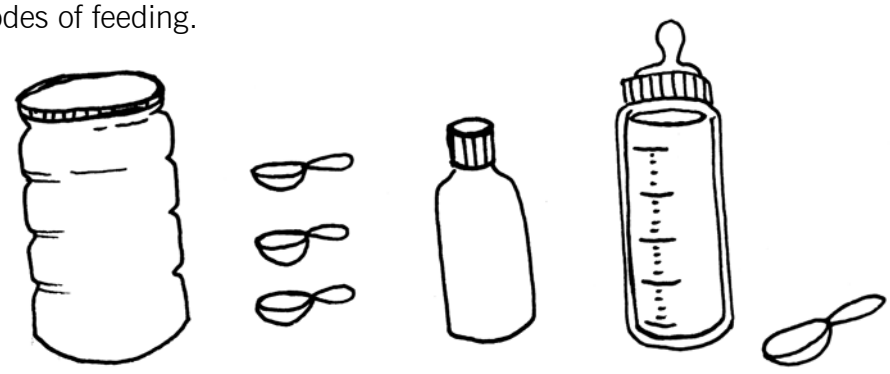
What do we mean by exclusive breastfeeding, exclusive formula feeding and mixed feeding?

Exclusive breastfeeding is when a baby receives nothing but breast milk (not even water), except for liquid vitamins or medicines.

Exclusive formula feeding or replacement feeding is when you feed a baby only with formula milk specially made for babies.

Mixed feeding is when a baby receives both breast milk and other liquids or foods.

These are sometimes called modes of feeding.



There are different views about which is best!

It is important that we acknowledge that there are different and sometimes strongly held views, about infant feeding. This is particularly true about infant feeding and HIV-positive mothers.

It is also important to understand that some views about infant feeding are based on proper scientific research, but that sometimes people hold strong views for other reasons.

In this section we will look at what we know about infant feeding based on scientific research and international policy and guidelines. We hope to give accurate information to help an HIV-positive mother make an informed decision about which mode of feeding is best for her, her baby and their circumstances.

We will also look at some ways to reduce the risk of HIV transmission through breastfeeding with the help of ARVs.

It is also very important that we acknowledge a mother's own right to health and how her health will affect the risk of transmission to her baby through breastfeeding.

We will talk about how we need to balance the risk of HIV transmission with the potential risks to the baby of malnutrition or infections other than HIV. These can occur if circumstances are not safe for a mother to use formula milk.

We know that some of this information can be confusing and difficult but we hope to make things a little clearer.

Breastfeeding and the risk of mother-to-child transmission

Exclusive breastfeeding is generally the best way to feed an infant, (see pages 39–40).

However, for HIV-positive women, breastfeeding carries a risk of MTCT. HIV can be transmitted from mother to child during pregnancy, labour and delivery, and also through breastfeeding.

Research has shown that five to 20 per cent of babies born to untreated HIV-positive mothers who breastfeed will also become HIV positive (see table).

The MTCT rates shown are different because factors, particularly a mother's own health – CD4 count and viral load – will influence the risk of transmission. As we can also see from the table, breastfeeding for a long period can mean a higher risk of HIV.

Timing	MTCT rate
During pregnancy	5–10 %
During labour and delivery	10–15 %
During breastfeeding	5–20 %
Overall without breastfeeding	15–25 %
Overall with breastfeeding for six months	20–35 %
Overall with breastfeeding 18–24 months	35–45 %

However, these rates of transmission are for women and babies who are not receiving antiretrovirals. Recent research from several African countries has shown that the MTCT rate for a mother receiving HAART and breastfeeding can be as low as one per cent.

Reductions in transmission risk have also been reported for breastfeeding mothers who do not need treatment for their own health and whose babies receive ARV prophylaxis.

These findings are of major importance for HIV-positive women choosing how to feed their infants. Both WHO and the South African guidelines can now make recommendations about using ARVs to reduce the risk of HIV transmission through breastfeeding.

In industrialised countries, HIV-positive mothers are always advised to formula feed their babies. If mothers do this exclusively there is no risk of HIV transmission to a baby through feeding.

But these mothers and infants have adequate nutrition and access to clean water, formula milk and sterilising equipment. This is not always the case in South Africa.

An important point to note is that if an HIV-negative mother sero-converts and becomes HIV-positive while she is breastfeeding, her baby is more at risk of becoming HIV-positive. This is because when somebody sero-converts, their viral load is very high.

Many babies are infected this way (and you put yourself at risk), so it is very important not to have unprotected sex when you are breastfeeding.

A mother's own health

As we said before, a woman's own right to health cannot be stressed enough. In addition, a healthy mother plays a critical role in the health of a child, as she is usually the main caregiver. A child's survival and health is very closely linked to the survival and health of his/her mother.

Our guidelines now recommend treating pregnant women at 350 cells/mm^3. This is good news for both mothers and babies. One Zambian study showed that about 80 per cent of postnatal transmissions, that is during breastfeeding, and almost 90 per cent of maternal deaths occurred in women with CD4 counts below 350 cells/mm^3.

HIV-positive women who are eligible for treatment must be identified and treated.

Breastfeeding vs formula feeding and nutrition

From a nutritional point of view there is no doubt that breast milk has many advantages over formula milk.

Exclusive breastfeeding provides a baby with all the nutrients he or she needs up to six months old.

Breast milk contains hundreds of ingredients including proteins, vitamins, fats and carbohydrates

perfectly tailored to the needs of an infant. It also provides sufficient liquid for a baby up to six months old.

Breast milk contains many antibodies to protect babies from infection. Rates of diarrhoea are higher in formula fed babies compared to breastfed infants, even in homes with good hygiene. Breast milk also protects the lining of the baby's intestine.

Breast milk changes its composition, both during one feed and over the months that the baby continues to drink from the breast.

After six months breast milk still provides much of these nutritional and other requirements. Research shows that it provides 60–80 per cent of nutritional requirements between six and 12 months, and 35–40 per cent of a baby's nutritional needs from 12–23 months.

Because the composition of breast milk is very complicated and not completely understood by scientists, it is not possible to exactly mimic it in a formula.

The other advantages of breastfeeding are that it is easy, clean, portable, free and the perfect temperature for a baby. This means that a mother does not require formula, bottles, sterilising equipment, access to clean water and heating, things usually needed to safely formula feed a baby (see page 41).

For all these reasons research has found that, in some situations, not breastfeeding a baby can lead to an increase in infant illness and death.

The big disadvantage, though, is that there is always a risk of HIV transmission from mother to baby through breastfeeding. Although, if a mother is receiving HAART or the baby receives NVP prophylaxis, the risk can be very low.

Also, if you need to return to work and/or your baby needs to be looked after by another caregiver, formula feeding is more practical.

The risks and benefits of both types of feeding can vary greatly from one setting to another, but can be difficult to assess.

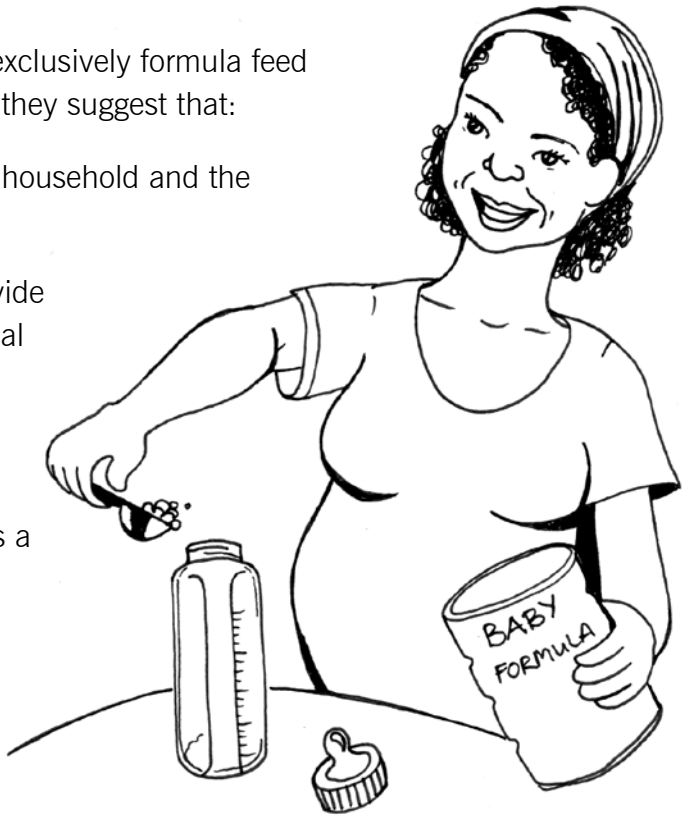
Nomawethu Ndindwa's story on breastfeeding

My neighbours were pressurising me to breastfeed but I refused because I knew that there was a chance of transmitting the virus to my precious babies. One of my neighbours told me that I won't transmit the virus if I breastfed but, because I knew better, I didn't. The only problem was that the clinic was only giving me one tin of formula a month instead of the eight tins I needed, and this was very expensive for me.

Conditions needed to safely formula feed

Experts have set up policies and guidelines to help with this decision.

The WHO recommends that in order to be able to exclusively formula feed the conditions need to be appropriate to do so and they suggest that:



- safe water and sanitation are available in the household and the community;
- a mother (or other caregiver) can reliably provide sufficient infant formula milk to support normal growth and development of the infant;
- the mother or caregiver can prepare the formula in a clean manner and frequently enough so that the formula is safe and carries a low risk of diarrhoea and malnutrition;
- the mother or caregiver can, in the first six months, exclusively feed the infant formula;
- the family is supportive; and
- the mother or caregiver can access healthcare that offers comprehensive child health services.

Some studies have reported good results where free and supported formula feeding was provided in Africa, including South Africa.

Vatiswa's story on cup feeding

My name is Vatiswa Kamkam. I am an HIV-positive mother to a beautiful baby girl. I was trained during my maternal clinical visits to cup feed. My experience with cup feeding is that it takes longer to feed the baby than it would with a bottle, and therefore more patience is required. One can also become stressed because you are not always sure whether the baby has had enough milk or requires more.

Cup feeding carries less risk of becoming contaminated by bacteria and germs because you feed the baby and clean the cups immediately. A bottle can be left unfinished and lie around and be exposed to germs. This means cup fed children are less likely to get diarrhoea. The problem is that these cups are not always available and so when you leave the hospital you have no choice but to bottle feed.

Our guidelines state that free formula will be provided until infants are at least six months old, and mothers should be given practical guidance on how to safely prepare the formula. This should include information on cup feeding, which can be safer than using a bottle.

A mother and the clinic she attends need to carefully consider these conditions. In some cases exclusive formula feeding will not be possible.

Mothers who choose to formula feed exclusively need to be supported by their health workers and this should be discussed at every clinic visit. Mothers also need support outside the health facility from family and friends to help avoid breastfeeding.

So what about safer breastfeeding?

As we explained, our guidelines now recommend breastfeeding if a mother is on lifelong ARV treatment or, if she is not, that her baby receives daily NVP prophylaxis.

This carries a very low risk of transmission if you are adherent. Breastfeeding is also good for the baby.

How and when do I introduce foods and wean if I am breastfeeding?

South African and WHO guidelines recommend exclusive breastfeeding for the first six months of a baby's life for mothers on HAART.

When the baby is six months old, appropriate complementary food should be introduced and breastfeeding continued until 12 months of age.

Introducing mixed feeding before six months old is not a good idea as this can increase the risk of childhood infections.

Breastfeeding mothers not on HAART, who decide to stop breastfeeding at any time, should do this gradually over a month. The baby should continue to receive daily nevirapine until a week after breastfeeding is stopped.

Healthcare services need to follow up on all babies born to mothers with HIV and offer feeding and nutritional advice and support.

Family planning

Planning your family and your right to have a baby

HIV-positive women, like any other women, may wish to plan their pregnancies, limit their family, or not have any children at all. This is called reproductive choice and it is our right.

Providing good contraceptive services can also reduce the rate of MTCT considerably (it is at least as effective as single dose nevirapine alone!).

Many African studies in HIV-positive women show very high rates of unintended pregnancies: 50 per cent in Cote D'Ivoire, 75 per cent in Rwanda, 85 per cent in South Africa and over 90 per cent in Uganda.

In humans, conception or fertilisation takes place when a sperm from the man penetrates the cell membrane of the egg from a woman. This can take place when we have sex without contraception, or if contraception fails.

If we do not want to have a baby, we can prevent pregnancy both before and after conception.

In order to prevent conception we need to use either:

- a physical barrier to prevent the sperm from coming into contact with the egg such as a condom; or
- hormones to stop the process of making the egg or to prevent the sperm reaching the egg, such as an injection or Pill; or
- surgery to stop the sperm's access to the egg. This is known as tubal ligation. Or a man could have a vasectomy.

If conception has already taken place and we want to prevent the pregnancy continuing, we can either take the morning-after pill immediately after or terminate the pregnancy in its early stages.

Health workers must enable our reproductive choices and rights with counselling and appropriate provision of services. This must happen at HIV diagnosis and throughout care and treatment.

Here are some of the contraception and reproductive health options most commonly used in South Africa:

Contraception

Many women who have not been well with HIV/AIDS and start taking ARVs find that, as they begin to feel better, their desire to have sex returns. So, for this and other reasons associated with better health, taking ARVs can increase fertility.

It appears that fertility can return very quickly after starting HAART. In a study in Uganda, a large percentage of women fell pregnant after starting, despite not changing their sexual practices . It seems that HIV depresses fertility, and that HAART quickly gets you back to normal.

Often getting well also means that we want to have a child, as we have heard from some of the stories in this handbook.

For some women this is not the case. For these women it is very important that they receive appropriate contraceptive services as part of their HIV care.

To use contraception effectively we need a basic knowledge of reproduction. We also need to be able to follow written or explained instructions. As with your HIV treatment and care, make sure that you ask questions if there is anything you don't understand.

Male condom

Condoms protect HIV-positive people from infecting their partners. They also protect us from sexually transmitted infections (STIs) such as gonorrhoea and chlamydia. In one year, three per cent of women will become pregnant even if they and their partners use condoms correctly every time they have sex. Condoms are free at clinics and community groups. They can also be bought over the counter at pharmacies, cafés and supermarkets.

Female condom (Femidom)

This is a polyurethane sheath with two flexible rings at each end. Female condoms are also protective against HIV. They are less likely than male condoms to leak or break during sex. Female condoms are 79 per cent effective against pregnancy with "typical use" and 95 per cent with "perfect use". They can be bought over the counter at pharmacies and are also available at some clinics.

Injectable contraception

This is an injection containing the hormone progestogen. The hormone progestogen stops ovulation and thickens the mucus around the cervix, which makes it difficult for sperm to get into the womb.

These injections are long lasting. Depo-Provera, the most commonly used contraceptive injection in South Africa, lasts 12 weeks. Injectables do not protect us from HIV or STIs. They are widely available and free of charge at most clinics. Only a doctor or nurse can give you an injection.

Oral contraceptives (the Pill)

These are small tablets containing either two hormones, oestrogen and progestogen (combined pill) or just progestogen.

They mostly work by stopping ovulation, which means the woman does not release an egg for fertilisation. They also thicken the mucous around the cervix making it difficult for sperm to get into the womb.

There are many types of oral contraceptives available in South Africa. Oral contraceptives must be taken the same time every day to be effective. With "perfect use", oral contraception can be 99 per cent effective. They offer no protection against HIV. Some research suggests oral contraceptives could actually increase transmission risk. Some ARVs and TB drugs interact

with oral contraceptives making them less effective, so you will need to check this with your health worker.

The Pill is available free from clinics, but you will need a prescription from a doctor.

Ovary is one of a pair of female reproductive glands (ovaries) that produce eggs or ovum.

Ovulation is when an egg is released from the ovary. This happens about 14/15 days from the first day of your last period. When ovulation takes place, the egg is released into the fallopian tube for fertilisation.

Fallopian tubes are found on the upper outer sides of the uterus.

Uterus (or womb) is a hollow, pear-shaped organ located in a woman's lower abdomen. The fertilised egg implants in the uterus and develops.

Emergency contraception (morning-after pill)

These are tablets with higher doses of the same hormones that are found in the combined pill.

They work by preventing your ovaries from releasing an egg and altering the lining of the womb, so a fertilised egg can't embed itself there.

To prevent pregnancy, these are most effective when taken within the first 24 hours of unprotected sex, but can be taken up to 72 hours after unprotected sex, although then they are less effective. The morning-after pill should be offered with PEP by rape centres. They are free at clinics and can be bought without a prescription at a pharmacy.

Post exposure prophylaxis or PEP means giving someone a short course of antiretrovirals after they have been exposed to HIV. This needs to be done within 72 hours of exposure.

Tubal ligation (sterilisation, getting your tubes tied)

This is a surgical procedure that makes it impossible for a woman to conceive. During tubal ligation, the fallopian tubes are cut or blocked in order to close off the sperm' s access to the egg. This is a very effective method of preventing pregnancy.

Younger women are less likely to be offered or choose this method. It is more often a choice for a woman who has already completed her family.

A woman with HIV cannot be sterilised unless she agrees that this is what she wants.

If a woman with HIV chooses to be sterilised, the hospital must respect her decision. She does not have to discuss her decision with her husband or get his consent.

Termination of pregnancy (TOP) or abortion

Termination of pregnancy (TOP) or abortion is when a woman decides to end her pregnancy by medical or surgical means.

The Choice on Termination of Pregnancy Act gives all women the right to have safe and legal terminations.

When a woman has a right to termination

In the first 12 weeks of pregnancy a woman in South Africa can have a medical abortion on request. This means that she does not have to give a reason for wanting the termination.

You do not need to get consent from anyone even if you are younger than 18 years old.

In the first 12 weeks, the procedure is simple.

Medical abortion means terminating a pregnancy with abortion-inducing medications. The most common regimen includes two medications: mifepristone, followed in 1–2 days by misoprostol.

Mifepristone blocks the production of progesterone which is needed to sustain the foetus.

Misoprostol causes the uterus to contract and helps to expel the pregnancy.

Medical abortion is very safe and major complications associated with medical abortions are extremely rare.

In South Africa, nurses who have undergone special training provide the majority of medical abortions.

Between 13 and 20 weeks you can still have an abortion, but will need to get a doctor's consent.

A woman can only have a termination after the 20th week of her pregnancy if a doctor, after discussing it with another doctor or a registered midwife, believes that the pregnancy could be dangerous for the woman or may result in a deformed baby.

Later abortions require surgery rather than medication.

If you need to have an abortion:

- Ask your doctor to refer you to a hospital or clinic where terminations take place.
- Go to a non-profit clinic that assists women with advice and care on issues of pregnancy and reproduction.
- Visit the hospital in your area that the government has set aside to do terminations. These are called designated hospitals.
- Go to the nearest doctor or nurse at your local primary healthcare clinic.

- Consult a counsellor at a community centre for a referral and counselling.
- Visit a social worker in your district for support.

Sometimes healthcare workers do not give women the right information because they think that it is wrong for a woman to terminate her pregnancy.

At other times, healthcare workers have insisted that a pregnant woman living with HIV/AIDS has a termination.

Principles affecting decisions about termination

- An abortion can only take place with the informed consent of the woman.
- A woman cannot be forced to have an abortion because she has HIV.
- Every person has a right to have a family, and a hospital must help a woman make an informed choice about terminating or continuing with a pregnancy.

Both are against the law, as only a woman has the right to decide whether or not she wants to continue with her pregnancy. If this happens to you, you should lodge a complaint with the Commission on Gender Equality (CGE) or the Department of Health.

Where will the termination take place?

The termination will take place at a hospital or clinic that has been authorised to do terminations by the Minister of Health. Social workers, doctors, nurses and midwives will be able to advise a woman where the nearest place is.

Will I be counselled before a termination?

The decision to end a pregnancy is often difficult for a woman to make. It is important to get support from people close to you if possible, or from a health worker or counsellor if you cannot talk to your family or friends.

You should be provided with counselling both before and after the termination. The counselling will help you think about all the options that are available and allow you to make the decision that is best for you.

Do I need to get my husband's consent before I terminate a pregnancy?

No! The Choice on Termination of Pregnancy Act says it is not necessary for a woman to ask her husband before she decides to end her pregnancy.

What needs to be done?

What needs to be done to ensure that mothers and babies receive the best possible healthcare?

The key to improving PMTCT:

- Increasing take-up of the programme. One big problem is that women are not accessing the services that they need;
- Identifying and ensuring women in need of treatment for their own health receive it as a matter of urgency;
- Monitoring and evaluating the programme on a regular basis. Otherwise how do we know what we are achieving?
- Ensuring women have access to good contraception and TOP services.

We also need to look after women's health whether they are pregnant or not in ways such as screening and treating for HPV and cervial cancer. And as well as identifying and treating pregnant women at 350 we need to work for this to be the recommendation in South Africa for everyone with HIV.

Conclusion

One of the happiest moments in a couple's life is the discovery that they will be having a baby. The news of pregnancy is almost always met with some degree of shock and surprise but soon after followed by joy and excitement for most. In South Africa as in many other parts of the world it is also a time when a woman first encounters the issue of HIV when this routine antenatal test is done.

The news of an HIV positive status, is also met with shock and often disbelief followed later by a variety of emotions mostly centering around fear, fear of the unknown. It is this fear, added to many myths and misconceptions around HIV that lead many women to either avoid HIV testing or avoid dealing with the result. This understandable yet unfortunate set of emotions often leads to unwise choices and an avoidance of scientifically sound interventions that have drastically improved the outcomes for both mother and baby.

This handbook, aims to provide the essential pillars of knowledge to enlighten newly pregnant mothers and their partners (as well as all others ever intending to have children) about HIV and pregnancy. It provides some basic and fundamental knowledge on vertical transmission and upon this foundation illuminates the ways interventions aimed at PMTCT work.

This handbook should be essential reading for any adult, male or female, HIV positive or negative, ever intending to have a child.

As HIV is the leading cause of maternal deaths in our country, and one of the leading causes of under five mortality, we all need to learn more about what can be done to prevent this. Advances in medical science in the last 5–10 years have shown that we can very significantly reduce deaths and illnesses in mothers and babies through sound and often simple interventions. So successful have these interventions been – mostly due to the appropriate use of antiretroviral therapy – that reproductive choices for people living with HIV have become possible.

The stories of personal experiences with HIV during pregnancy greatly assist the reader in understanding the rationale for the actions recommended and the ease at which many of these can be followed, with good outcomes.

Lastly, prevention of mother to child transmission starts and ends in the community, in households and not a phenomenon of the labour ward. Knowledge of the interaction of HIV and pregnancy is therefore everybody's business!

Professor Ashraf Coovadia

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