

# Guide to HIV, pregnancy & women's health

## September 2011

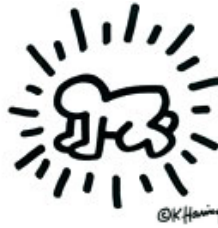


HIV i-Base  
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Watch for out-of-date information

**Diagnosed with HIV in pregnancy**  
**How HIV is transmitted to a baby**  
**Mothers' health**  
**Having an HIV-negative baby**

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This booklet is about HIV and pregnancy. It explains what to do if you are diagnosed with HIV in pregnancy. It also explains what to do if you already know you are HIV positive and decide to have a baby. The booklet includes information about mothers' health, using antiretrovirals during pregnancy and the babies' health. It includes information on how to have an HIV negative baby if you are HIV positive. It also includes information about safe conception for couples where one partner is positive and one is negative.

The guide was written and compiled by Polly Clayden for HIV i-Base. Thanks to the advisory board of HIV-positive people, activists and health care professionals for comments; the Monument Trust for funding this publication, the people who shared their stories, and to

Memory Sachikonye for helping to find them. Artwork copyright Keith Haring Studio.

Disclaimer: Information in this booklet is not intended to replace information from your doctor. Treatment decisions should always be taken in consultation with your doctor.

## Introduction

This is the 5th edition of the i-Base pregnancy guide.

Since our last edition, research findings have been reported that have informed a few changes in our guide. These include:

- An expanded section on safe conception for couples where one partner is HIV negative and one is HIV positive. This has more emphasis on safer natural conception. So although most of the information included in the booklet is for HIV positive women, this section is also relevant to HIV negative women with HIV positive men.
- That it is less important and likely that you will receive the drug AZT in your combination.
- A stronger emphasis on making sure your viral load is undetectable at delivery. Also more details about when to start treatment to ensure that you achieve this for different viral load levels.

- More information on safety and side effects of anti-HIV drugs. Including on the protease inhibitor atazanavir that is increasingly being used in pregnancy.
- A strong recommendation that all pregnant women should be vaccinated against flu.
- A continued strong recommendation on the importance of complete avoidance of breast feeding despite new research relevant to countries where this is not possible.
- We have also included some personal stories.
- The excellent news is, with good management focusing on a woman's health and choice, there is little risk of transmission to her child for an HIV positive mother delivering in the UK today.

Our most recent reports show a 1 in 1,000 transmission rate for women receiving HAART with an undetectable viral load of less than 50 copies/mL whether she has a planned vaginal or planned Caesarean delivery.

This is the lowest reported and represents a significant advance in the information available to women planning a family or already pregnant.

We explain what all these options mean and when they are appropriate. Excellent news too is that people with HIV are living longer and healthier lives so an HIV positive mother in the UK today can also expect to be around to watch her child grow up!

British HIV Association (BHIVA) and Children's HIV Association (CHIVA) Guidelines for the Management of HIV Infection in Pregnant Women 2008 are online at:

[http://www.bhiva.org/  
PregnantWomen2008.aspx](http://www.bhiva.org/PregnantWomen2008.aspx)

British HIV Association, BASHH and FSRH guidelines for the management of the sexual and reproductive health of people living with HIV infection 2008 are online at:

[http://www.bhiva.org/documents/  
Guidelines/Sexual%20health/Sexual-  
reproductive-health.pdf](http://www.bhiva.org/documents/Guidelines/Sexual%20health/Sexual-reproductive-health.pdf)

Some of the research we discuss in this booklet has been reported since the guidelines were published, but they are currently being revised. What we talk about reflects the treatment you should expect in the UK in 2011.



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## Background and general questions

This booklet aims to help you get the most out of your own treatment and care if you are considering pregnancy or during your pregnancy.

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 the health of your baby.

### If you have just been diagnosed with HIV

You may be reading this guide 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 about both at the same time.

Both pregnancy and HIV care involve many new words and terms. We try our best to be clear about what these terms really 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.

There are lots of people, services and other source of information to help you. The advice that you

receive from these sources and others may be different to that given to pregnant women generally. This includes information on medication, Caesarean section (C-section) 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 were diagnosed during your pregnancy. You may need to make some difficult decisions more quickly.

Whatever you decide to do, make sure that you understand the advice you receive. Here are some tips if you are confused or concerned as you consider your options:

- Ask lots of questions.
- Take your partner or a friend with you to your appointments.
- 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.

The only “correct” decisions are those that you make yourself.

You can only make these after learning all you can about HIV and pregnancy, and with your healthcare team.

I was diagnosed via antenatal testing when I was three months pregnant. What a time to receive bad news! I had a lot to think about and at the same time start treatment straight away.

The support I got from my group was invaluable in helping me appreciate the treatment and take it as prescribed. The thought of having a healthy baby made me determined to follow everything in detail.

I had a bouncing HIV negative baby boy thanks to ARVs.

After he was born I stopped my medication, on my doctors recommendation, as I did not need it for myself. My CD4 is quite good (above 600) and I had an undetectable viral load at the time of my baby's delivery.

Jo, London

## Can HIV positive women become mothers?

Yes, and HIV treatment makes this much safer.

Women around the world have safely used antiretroviral (ARV) drugs in pregnancy now for over 15 years. Currently this usually involves taking at least three anti-HIV drugs, a strategy called combination therapy or HAART.

These treatments 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 children again).

## 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, about 25 percent of babies born to HIV positive women will be born HIV positive. One in four is not good odds, though, especially because modern HIV treatment 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. 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.

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 therapy is to reach an undetectable viral load.

This is particularly important at the time of delivery. Other risk factors include premature birth and lack of prenatal HIV care.

Practically all risk factors point to one thing: looking after mother's health.

Some key points to remember:

The mother's health directly relates to the HIV status of the baby.

Whether the baby's father is HIV positive will not affect whether the baby is born HIV positive.

The HIV status of your new baby does not relate to the status of your other children.



I've often said that having an HIV diagnosis does not change who you are. Like many young women I had always wanted to be a mother. In some way, having a positive diagnosis made me think about it even more.

I had my baby five years after I was diagnosed. That was way back in 1998. I guess I was lucky in a lot of ways because by the time I made the decision to have a baby I'd had a lot of peer support, information and met a lot of other HIV positive women, who also had either been diagnosed antenatally, or had children after their diagnosis.

One of the most difficult things during and after my pregnancy was the uncertainty about whether - even taking up all the interventions that were available to me – my baby would be born HIV-negative.

I cannot describe my feelings when I finally got the all clear for my beautiful baby. All the worry, fear and uncertainty were definitely worth the wait!

Angelina, London

### Combination therapy

or **HAART** (Highly Active Antiretroviral Therapy) are terms used to describe a strategy of using three or more drugs to treat HIV.

- Anti-HIV drugs are not effective for treating HIV individually (monotherapy), but they can be very effective in combination.
- For more info see the i-Base *Introduction to Combination Therapy*.

### Are pregnant women automatically offered HIV testing?

It is now recommended in many parts of the world. In the UK healthcare providers have been required since 1999 to offer and recommend that all pregnant women have an HIV test. This is now part of routine prenatal care.

It is important for a woman to take 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.

This knowledge also means that she can be aware of how she can protect her baby from HIV, if she tests positive.

### How do HIV drugs protect the baby?

Reducing the risk of a baby becoming HIV positive was an early benefit of anti-HIV therapy.

PACTG 076 is the name of a famous joint American and French trial whose results were announced in 1994. This was the first study to show that using the drug AZT could protect the baby. Mothers took AZT before and during labour, and the baby received AZT for 6 weeks after birth. This reduced the risk of the baby becoming HIV positive from 1 in 4 (25 percent) to 1 in 12 (8 percent).

After 1994, this strategy was recommended for all HIV positive pregnant women in many industrialised countries.

Even further advances have been made over the last few years, especially since combination therapy became more common during the late 1990s. Transmission rates with combination therapy are now less than one percent.

AZT is still the only drug licensed for use in pregnancy. There is also a lot of experience of using it. Some doctors may still prefer to include it in a woman's combination if she is pregnant.

However, a recent British and European report showed over 1000 women who had received non-AZT

**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 (MTCT), perinatal or vertical transmission.

- Children who become HIV-positive in this way are called “vertically infected” 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

- Viral load is one measurement of the progression of HIV. The goal of treatment is to get your viral load to be undetectable, which is currently considered to be 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 almost zero.

### **Resistance**

- If you just take one drug (monotherapy) or a combination of drugs that are not strong enough to get your viral load undetectable, then HIV can become resistant to the drugs.
- If the virus is resistant to a drug it will no longer work as well or it may not work at all.
- To avoid resistance, you need a combination of at least three antiretroviral drugs.
- It is important to avoid resistance in pregnancy.
- However using short-term monotherapy with AZT to prevent mother-to-child transmission (this is only used in some cases where a mother has a very low viral load) carries a very low risk of resistance.

HAART in pregnancy. This report found that women receiving non-AZT HAART were no more likely to transmit HIV to their babies or have a detectable viral load than those on AZT-containing HAART. Nor were their babies more likely to have abnormalities.

In the UK we are using AZT less and less in HIV regimens and other drugs like tenofovir (which is easier to tolerate than AZT) are being used more. If you are already on HIV treatment it is quite likely that you will be on a non-AZT regimen and, provided that it is working well, that your doctor will not change this.

A general rule of thumb is, what's best for mum is best for baby.

It is important to remember though that despite huge advances and successes, there are still risks to be considered when using combination therapy for pregnant women. We are still learning about combination therapy in pregnancy.

You will need to discuss the benefits and risks of treatment with your healthcare team. This will include known and unknown short- and long-term factors. Nevertheless, the benefit of combination therapy far outweighs the risk.

## **Is it really safe to take HIV medicines during pregnancy?**

Pregnant women are generally advised to avoid taking any medications. However, this is not the case when considering the use of HIV treatment 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.

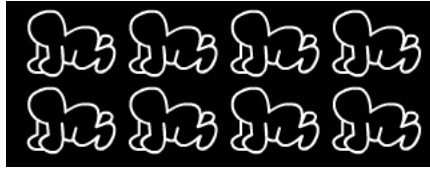
At the same time, however, many thousands of women have taken therapy during pregnancy without any complications to their baby. This has resulted in many healthy HIV negative babies.

During your prenatal discussions, you and your doctor will weigh up the benefits and risks of using treatment to you and your baby.

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

<http://www.apregistry.com>

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



When most of everything felt right, my health and relationship, having a baby, after more than 20 years since my last child, was the best feeling. After discussions with my partner and my doctor, I decided to have a baby. We did this while continuing with my current meds and of course not breastfeeding.

I was determined to do everything in my power to have an HIV-negative baby. Combination therapy has fulfilled my dreams of becoming a mother again.

Jenny, London

## Will being pregnant make my HIV worse?

Pregnancy does not make a woman's own health get any worse in terms of HIV. It will not make HIV progress any faster.

However, being pregnant may cause a drop in your CD4 count. This drop is usually about 50 cells/mm<sup>3</sup>, but it can vary a lot. This drop is only temporary. Your CD4 count will generally return to your pre-pregnancy level soon after the baby is born.

The drop should be a concern if your CD4 falls below 200 cells/mm<sup>3</sup>. Below this level, you are at a higher risk from OIs.

These infections could affect both you and the baby, and you will need to be treated for them immediately if they occur. In general, pregnant women need the same treatment to prevent opportunistic infections as people who are not pregnant.

Also sometimes 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.

## Additional info

This booklet is about HIV and pregnancy. Other important aspects of HIV treatment and care are described in detail in other i-Base guides, including:

- Introduction to Combination Therapy
- Guide to Changing Treatment
- Avoiding and Managing Side Effects
- Hepatitis C for people living with HIV
- Sexual Transmission and HIV Tests

These free booklets provide additional information on the basics of using and getting the best out of your treatment. They also further explain words and phrases introduced here that may be unfamiliar or confusing, including CD4, viral load and resistance.

We hope that you will use all of these booklets together when you need them. Your clinic may have copies of any or all of them. You can also order them online:

<http://www.i-base.info>

*Regardless of pregnancy, women should receive optimal treatment for their HIV status*

### Information phoneline

i-Base provides a specialised free telephone information support service at the following telephone number: 0808 800 6013. If you want to talk to someone about HIV treatment and pregnancy, please give us a call and we will try to help. The service is available from 12-4 pm on Monday, Tuesday and Wednesday.

We also offer an information service by email from:

[questions@i-base.org.uk](mailto:questions@i-base.org.uk)

Please also note that this guide focuses on HIV and pregnancy. We have written it for women who planned to be pregnant or are happy to be so. We have another guide in the pipeline focusing on contraception, termination of pregnancy and other aspects of HIV positive women's health.

There is also a lot of information out there on all aspects of good health in pregnancy such as not smoking, eating well and avoiding alcohol.

Please talk to your health care team if you need additional support and information.

- **CD4 cells** are a type of white blood cell that helps our bodies fight infection. These cells are also the ones that HIV infects and uses to make copies of itself, and then to spread further.
- Your **CD4 count** is the number of CD4 cells in one cubic millimetre (mm<sup>3</sup>) 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 400-1,600 cells/mm<sup>3</sup>. 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<sup>3</sup> is considered to be low, and nearly all treatment guidelines recommend starting treatment before the count reaches that level. You are very vulnerable to infection if you have a CD4 count below 200 cells/mm<sup>3</sup>.

## Protecting and ensuring the mother's health

Your own health and your own treatment are the most important things to consider to ensure a healthy baby.

This cannot be stressed enough.

Sometimes medical research can forget the fact that HIV positive pregnant women are people who need care for their own HIV infection.

This can sometimes be neglected or forgotten by mothers and healthcare workers when the baby's health is the main focus. You should not forget this, though: your health and care are very important.

Overall, your treatment should be largely the same as if you were not pregnant.

Prevention of transmission and the health of your baby have a direct link to your own care.

Prenatal counselling for HIV positive woman should always include:

- Advice and discussion about how to prevent mother to child transmission.
- Information about treating the mother's own HIV now.
- 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.

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





### Principles of care

- A mother should be able to make her own informed choices about how to manage her pregnancy.
- She should be able to choose her own treatment during the pregnancy.
- Healthcare workers should provide information, education and counselling that is impartial, supportive and non-judgemental.
- HIV should be intensively monitored during pregnancy. This is particularly important as the time of delivery approaches.
- Opportunistic 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.
- Mothers should be able to make informed choices regarding how and when their babies will be born.

## Mother to child transmission

### How and why does transmission happen?

Despite remarkable achievements in reducing mother-to-child transmission (MTCT), we do not fully understand how it happens. What we do understand, though, is that there are many factors that affect transmission.

Of these, the level of the mother's viral load is the most important.

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 traveling 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. Usually it takes several weeks from when someone is infected until HIV shows 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 make in utero transmission more likely.

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

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

**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, vagina, lungs, and stomach). Glands in the mucosa make mucous, a thick, slippery fluid. A mucosal lining is also called a 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:

- 50 percent of babies who turn out to be infected 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 success in preventing it happening. This includes:

- Treatments that have reduced transmission risk, even when given only in labour

- Delivering the baby by Caesarean section before labour starts.

If it takes a long time to deliver after the membranes have ruptured (waters breaking) or if there is a long labour, the risk of transmission in women not receiving ARV treatment or prophylaxis is increased.

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.

In the UK all HIV positive women are recommended to formula feed their babies to protect them from HIV.

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!

## Planning your pregnancy

### Preconception, planned pregnancy, and your rights to have a baby

Many HIV positive women become pregnant when they already know their HIV status. Many women are also already taking anti-HIV drugs 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—whether this pregnancy was planned or not.

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

- Consider your general health.
- Have appropriate check ups.
- Treat any sexually transmitted infections (STIs).

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

It is reassuring that over 98 percent of HIV positive pregnant women have uninfected babies in the UK currently.

Choose a healthcare team and maternity hospital that supports and respects your decision to have a baby.

If you are not supported in this decision, then arrange to see a doctor and healthcare team with more experience in dealing with HIV.

You may not be able to travel to a centre with this expertise. In this case, you should contact them for advice, support and to find out your rights.

In this section, as well as options for HIV positive women (with either negative or positive partners) wishing to get pregnant, we look at safer conception for HIV negative women with HIV positive partners.

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 serodifferent (the medical term is serodiscordant) couples. (These are terms for when one partner is HIV positive and the other HIV negative.)

If serodifferent couples have unsafe sex there is always a potential risk of transmitting HIV. Even when politely called a “conception attempt” under the safest conditions, there is always a theoretical risk, even when this is extremely low, that the HIV negative partner will contract HIV.

Until quite recently, conceiving through timed unprotected intercourse was rarely officially recommended.

Newer evidence though, supports this as a much more practical option and discussing this option with your healthcare providers is important.

I am HIV positive. My partner is HIV negative.

We have two beautiful daughters. Both conceived naturally. Both, like their mum, are HIV negative

We initially considered spermwashing, but we would have needed to use artificial insemination. This was extremely expensive and involved travelling and giving my partner hormone injections.

This was not the the way we wanted to have a baby.

We decided that the risk of transmission with someone who was undetectable for many years, extremely adherent and had no STIs was very low.

So we bought a cheap ovulation test and did it naturally... and it worked... twice!

Mauro, Italy

With the help of their healthcare team, couples can weigh up, based on a growing body of research, the risks and benefits in their individual case, and whether the risk is acceptable to them.

HIV transmission during vaginal intercourse depends on several factors. For couples in stable, monogamous relationships that wish to conceive, the most important considerations are:

- The viral load of the HIV positive partner.
- Whether there are other STIs.
- Frequency of intercourse.

For example, if an HIV positive man is in a monogamous relationship and not taking HAART the risk of transmission to his HIV negative female partner is estimated in some studies to be 0.1 to 0.3 percent for each act of intercourse.

The risk of transmission from an untreated HIV positive woman to an HIV positive man is estimated to be 0.03 to 0.09 percent.

The risk is a lot lower in people with an undetectable viral load in blood plasma taking HAART.

Viral load in plasma has quite good correlation with viral load in genital secretions.

But, HIV has been detected both in semen in HIV positive men and the fluid in the uterus and surrounding the ovum in HIV positive women, even when their viral load was undetectable with HAART.

Having an STI (eg syphilis, chlamydia) increases the HIV viral load in genital secretions but not in plasma.

It is difficult for doctors (or for us) to give sero-different couples precise advice. It is known that the risk of timed, unprotected intercourse, where the HIV positive partner is on treatment with an undetectable viral load for more than six months, is very low. But it is not completely zero.

Mathematical models have suggested a risk of 1 in 100,000 per act of intercourse.

Mathematical models are used a lot by scientists to answer “what if?” questions. They simulate real life situations with mathematical equations. Known information will be entered into a computer programme and the system will generate answers.

Answers from mathematical models are not the same as answers from real life research, but they can be pretty useful in helping us understand what an outcome is likely to be.

A very large study recently reported some very important news.

In May of this year, the results from the HIV Prevention Trials Network (HPTN) Study 052 provided proof that HAART can make HIV positive people less infectious to their HIV negative partners.

HPTN 052 is the first randomised controlled trial (RCT) to demonstrate a reduction in infection.

The study was multinational and conducted with over 1700 serodifferent couples. It compared the effect of starting HAART immediately - defined as a CD4 count between 350 and 550 cells/mm<sup>3</sup> – to delaying starting until the positive partner reached a CD4 count of less than 250 cells/mm<sup>3</sup>.

The results showed that starting HAART at higher CD4 counts lowered the risk of HIV transmission by a remarkable 96 percent. The study was stopped early as the benefits were shown more quickly than anticipated in the original design for the trial.

The only prospective study to look at transmission risk in serodifferent couples attempting to conceive naturally, where the HIV positive

man had an undetectable viral load on HAART, and the woman received pre-exposure prophylaxis (PrEP) was with 22 couples. In this study, intercourse was timed to the woman's fertile period and there was a 50 percent conception rate.

The same researchers had reported earlier from a retrospective review of 74 couples (52 with an HIV positive man and 22 with an HIV positive woman) in which the positive partner was on HAART, intercourse was timed, and there were no transmissions.

If you do decide that this is the most acceptable way of conception for you and your partner you need to make sure:

- The HIV positive partner is adherent.
- The HIV positive partner has regular viral load checks.
- Both partners have STI screening.
- Both partners have fertility screening.
- Both partners understand when the woman is most fertile.
- The HIV negative partner considers using PrEP.

Some clinics will ask you to sign a form confirming that you have received pre-conception counselling and that you fully understand the risks involved.



### Timing of conception attempt

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

Ovulation takes place about 14 days before the beginning of the woman's next menstrual cycle.

You are at your most fertile the day before and the day of ovulation as the egg survives about 24 hours. This is when conception can take place.

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

There are different ways to estimate your fertile time, usually by taking your temperature (your temperature increases at the beginning of ovulation) or by recording when your periods take place in order to work out when you are ovulating (called the calendar method). Chemists sell ovulatory kits that can help you work this out.

Your healthcare team can explain to you how to do this.

### Pre Exposure Prophylaxis or PrEP

This is when an HIV negative person takes antiretrovirals to prevent them from getting HIV. This method can be used can be used to help make a conception attempt safer.

One additional point should be stressed. Although a low number of conception attempts can be relatively safe, some couples do not return to safer sex afterwards. This sometimes results in the negative partner then becoming HIV positive.

HIV is still a disease that can affect 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.

### **When the man is HIV positive and the woman HIV negative**

When the man is HIV positive with a negative partner, if they decide against timed intercourse, protected by ARVs, as described, 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; sperm cells themselves do not carry 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.

The disadvantages of sperm washing are cost, access and lower rate of conception.

Very few clinics offer this service in the UK but the clinic with the most experience is the Chelsea and Westminster Hospital in London. The Chelsea and Westminster assisted conception unit can be contacted on 0208 746 8585.

It is not always possible to obtain this procedure on the NHS, but occasionally people were funded as part of a risk reduction intervention at this clinic.

Apart from the cost, one of the disadvantages of sperm washing is that it does not have a very high success rate for conception, compared to conceiving by having sex. It is very safe in terms as far as preventing HIV transmission is concerned, but it also means you will be conceiving your baby in a very medicalised environment. Many people find this difficult, especially if it does not lead to a successful pregnancy.

As the information about safe conception protected by ARVs makes it more acceptable for couples to use this method of conception, sperm washing is being recommended and used less and less.

I have lived with HIV for so long that I don't remember what it's like to live without it. I found it difficult to be HIV positive in the beginning. But once I learned to live with it, I decided to start living my life again.

I then realised I could do all the things that I thought HIV made impossible. I thought I could not live over 25 years, or ever have a successful relationship or have children!

So last year I told my partner, who is HIV-negative, that I would love to have a child and he agreed.

We talked about how to achieve this and the possible options. We settled on the least complicated if not entirely safe option – unprotected sex during my ovulation period. In a couple of months, I conceived!

My pregnancy was relatively easy. My obstetrician strongly advised that I go for a vaginal delivery as my CD4 was very good and my viral load undetectable.

My baby was tested for HIV a day after he was born. He has now had several negative results. He is now 6 months old and growing beautifully.

My partner remains HIV negative.

Millie, Bristol

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

The options are usually much simpler and cheaper in this situation. Do-it-yourself artificial insemination (self insemination) using a plastic syringe carries no risk to the man.

This is a very safe 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 before your period.

Different clinics may recommend different methods. One way is to have protected intercourse with a spermicide-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 in which both partners are HIV positive, some doctors still recommend safer sex to limit the possibility of reinfection with a different strain of HIV (or a resistant strain).

Reinfection is only a risk if one partner has extensive drug resistance and a detectable viral load, or neither partner is on ARVs. This should be the only reason that a couple should be discouraged to attempt to conceive naturally. Reinfection 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 reinfection:

- The risk will relate to viral load levels and be very low if you are on treatment.
- This consequence is only likely to be important if one partner has drug resistance, especially if they also have a high viral load.
- If you routinely practice safer sex, you may want to limit unprotected sex to the fertile period. You could also follow the advice for serodifferent couples.

## 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 serodifferent 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 serodifferent 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 6 months
- Has excellent adherence
- 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 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>

For HIV positive couples who do not practice safer sex now, 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 also very individual. All methods of becoming pregnant carry varying degrees of risk, and chance of success (and sperm washing and fertility treatment may involve a cost if you are unable to access them on the NHS).

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

### **Can I get help if I am having difficulty conceiving?**

**All couples could experience some fertility difficulties, regardless of who is HIV positive or if 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. Ask about the possibility of referral to a fertility clinic with experience of HIV.

### **Is fertility treatment available to HIV positive people?**

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

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

There will also be the same levels (which can be quite strict) of screening given to you as any couple accessing fertility treatment. Sometimes this will not be available on the NHS.

You may encounter resistance to this help because you are HIV positive. You can and should complain about this if you do.

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

## Prenatal care and HIV treatment

### What is prenatal care?

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

Prenatal care is not only about medicine and about tests. It includes counselling and providing information like this guide. It also includes advice on your general health such as taking exercise 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. This includes your obstetrician, midwife, paediatrician and other support staff.

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

Does every HIV positive woman need to use treatment in pregnancy?

Every pregnant woman with HIV with a CD4 count of about 350 cells/mm<sup>3</sup> or less needs to start treatment for her own health.

Women will also consider a short course of treatment during pregnancy, to prevent mother-to-child transmission. This is regardless of the mother's CD4 or viral load counts.

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

Usually it is best once you start HIV treatment, to continue for the rest of your life. In pregnancy people often use treatment just until delivery, then they stop.

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

UK guidelines recommend starting treatment while your CD4 count is about 350 cells/mm<sup>3</sup>. Treatment is not currently recommended at much higher CD4 levels unless you have HIV related health problems. However, studies show that HIV treatment can reduce the risk of transmission even with mothers who had low viral loads that are less than 1,000 copies/mL before they started treatment.

Transmission dropped from almost 10 percent in untreated women to less than one percent in women treated with anti-HIV drugs.

As a result, treatment or prophylaxis is offered to all HIV positive pregnant women, even those with CD4 counts over 350 cells/mm<sup>3</sup> who have never been on treatment before.

British HIV pregnancy guidelines recommend two options for women in this situation who have higher CD4 counts:

Use **Short Term Triple Antiretroviral Therapy (START)**. With START, you begin treatment during the second trimester at 20 to 28 weeks, and then stop after delivery. You can choose to plan a Caesarean section at 38-39 weeks or a vaginal birth.

Use **AZT monotherapy** (as in the 076 study) and have a planned pre-labour Caesarean section at 38 weeks.

The second option is only suitable for women with a high CD4 count and a low viral load who would not need to use ARV treatment for several years. This option is rarely used now.

Choosing START does not mean you will definitely not have a Caesarean section. You may need to for other obstetric reasons.

You will need to recognise the benefits and risks of these two options. Discuss and consider the following very carefully until you are happy with the approach you are going to use.

Benefits of START:

- Using three drugs will reduce your viral load to undetectable.
- You will have a choice over mode of delivery.

Risks of START

- You and your baby will be exposed to a greater number of drugs, which may increase the risk of premature delivery.

## What if I need treatment for my own HIV?

Guidelines currently recommend that all HIV positive people with CD4 counts of about 350 cells/mm<sup>3</sup> should be on treatment, including pregnant women. Treatment will also depend on when in your pregnancy you are diagnosed with HIV.

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

If you are diagnosed early on in your pregnancy, you may wish to delay starting treatment until the end of the first trimester.

This is the first 12 to 14 weeks from your last missed period. You may also want to delay treatment over this period if you already know your HIV status but have not yet started treatment.

There are two main reasons for delaying treatment.

The first is that the baby's main organs develop in the first 12 weeks in the womb. This is called organogenesis. During this time the baby may therefore be vulnerable to negative effects from any medicines, including anti-HIV drugs.



Studies have not shown any increased risk to babies whose mothers have used HIV treatment during the first trimester, compared to those who did not use treatment in this period.

A second reason to delay treatment is that most women will experience nausea or “morning sickness” in the early stage of pregnancy. This is very normal.

Symptoms of morning sickness are very similar to the nausea that can occur when starting HIV treatment. You do not want (or need) to have both at the same time. This can also make adherence harder.

If you feel rough because of morning sickness, you are unlikely to want to take any treatments that increase this nausea. And if you are unlucky and get bad morning sickness or are vomiting, this could cause problems with missed doses which may lead to the treatment failing and the development of resistance to anti-HIV drugs.

If morning sickness continues after the first trimester, you and your doctor should take this seriously as it could signal other problems.

If you want to begin treatment immediately, or need to start urgently because you have a low CD4 count, and high viral load, your doctor will recommend it.

### **When is the best time to start if I have a high viral load?**

A recent UK study looked at the best time to start treatment to ensure an undetectable viral load by the time of delivery. It recommended:

- Women with a viral load greater than 100,000 copies/mL should commence HAART without delay.
- Women with a viral load greater than 10,000 copies/mL should start HAART by 20 weeks.
- If the viral load is less than 10,000 copies/mL, HAART may be delayed to 26 weeks.
- If the viral load is greater than 10,000 copies/mL NNRTI-based HAART, where appropriate, may be more successful than PI-based HAART.

So, it is important to start treatment early if your viral load is high. This will mean you have the least risk of transmission and also more choice of how the baby is delivered.

### **What if I only discover I am HIV positive late in pregnancy?**

Treatment even for a short time with combination therapy can reduce your viral load very quickly by a large amount and some anti-HIV drugs help reduce the risk of HIV transmission by crossing the placenta to the baby and blocking the infection, regardless of the amount of HIV in the mother’s blood.

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

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

Women feel better. They are healthier. They are thinking about long-term relationships. They are thinking about a future and possibly a family.

It is now increasingly common for women who conceive while they are on treatment to continue on treatment throughout their pregnancy.

Studies have not shown any increased risk to the mother or baby from using continuous treatment throughout the pregnancy.

HIV drugs during pregnancy

## Which drugs should I use?

Like all decisions relating to HIV treatment, there are no hard and fast rules.

Your treatment should be individual. It should suit your own health and your own situation.

## Using triple combinations

AZT is still the only HIV drug licensed for use in pregnancy. There is also a lot of experience with this drug in pregnant women.

So some doctors recommend it during this time, particularly if a woman is starting treatment in pregnancy.

However, a recent British and European study looked at non-AZT HAART among pregnant women and found no difference in rates of mother-to-child transmission, undetectable viral load at delivery or abnormalities in the babies.

Use of other nucleoside analogues also increased over time – between 2006 and 2009 about 60 percent of women in this study received non-AZT HAART. Over 70 percent were already receiving non-AZT HAART before they became pregnant.

If you do not need to use treatment for your own health, you may decide to use START.

You will receive two nucleosides  
This third drug will probably be a protease inhibitor.

The protease inhibitor is most likely to be lopinavir boosted with ritonavir (called Kaletra and in one pill) or atazanavir boosted with ritonavir.

If you plan to stop treatment straight after your baby is born a protease inhibitor has an advantage over an NNRTI. Your body processes protease inhibitors relatively quickly. You can stop all the drugs in your combination at the same time with a low risk of resistance.

If you need to start treatment for your own health and continue, a drug that is often used is an NNRTI called nevirapine. This drug has been widely used in pregnancy.

There is however a caution against starting nevirapine-based HAART for women with CD4 counts above 250 cells/mm<sup>3</sup> because of a risk of liver (hepatic) toxicity.

Nevirapine appears to be safe for women with lower CD4 counts (below 250 cells/mm<sup>3</sup>). There is no concern with people who have used nevirapine successfully in their combination and now have a higher CD4 count on treatment.

You will probably receive nevirapine if you start your treatment with a CD4 count less than 250 cells/mm<sup>3</sup>.

As we explained above, if your viral load is greater than 10,000 copies/mL NNRTI-based HAART, where appropriate, may be more successful in getting your viral load to undetectable before delivery.

If you are already using combination therapy, and all is going well, you are likely to remain on the same combination. It is increasingly common for women to already be receiving HAART before they become pregnant.

If you are using efavirenz, ddI or ddI and d4T together, you may need to stop or switch those drugs.

This will also depend on what other choices are available to you.

If you have side effects, or your viral load is detectable, your doctor will also look for a possible switch in therapy.

Although it is rare, some women have even delivered babies on combinations of five or more anti-HIV drugs (sometimes called mega-HAART).

Finally, if you only find out that you are HIV positive very late into your pregnancy or in labour you will have specific treatment.

You are likely to be offered nevirapine, regardless of your CD4 count, because a single dose appears to be safe, nevirapine is absorbed very rapidly and is the most effective drug for reducing mother-to-child transmission in this situation.

As resistance to nevirapine develops easily, you need to use it with two other drugs. These are often AZT and 3TC (called Combivir, when together in one pill).

It is best to continue with a triple combination until your viral load is below 50 copies/mL. This will reduce the risk of resistance.

If your CD4 count is greater than 250 cells/mm<sup>3</sup> you will be given a boosted protease inhibitor, instead of continuing with nevirapine, for at least a week but ideally until your viral load is undetectable.

If your CD4 count is less than 350 cells/mm<sup>3</sup> you will be advised to continue HIV treatment.

You should only continue treatment if you are strictly taking every dose as prescribed.

In some circumstances, depending on the drugs you are using and your birth plan, you may also receive AZT directly into a vein (intravenously, IV) during labour.

### **Are any drugs not recommended in pregnancy?**

Efavirenz is not usually recommended in pregnancy.

This drug caused neural tube (the developing brain) damage in the developing foetus in a single animal study. It is important to note though that efavirenz is the only ARV that has ever been tested in this way.

So far there are no reports of a similar increased risk in human babies. As more women become pregnant when they are already

taking HAART, there have been more cases of women receiving efavirenz at this time.

For example in a British study of women receiving HAART at conception, 20 percent of women receiving an NNRTI received efavirenz.

There have been many more reports of women receiving efavirenz in pregnancy throughout the world that offer reassurance to mothers and doctors.

But, if other treatment options are available, there is a caution against its use. This is considered to be most important during the first 12 weeks of pregnancy when the neural tube is developing.

If you are already 12 or more weeks pregnant and have been taking efavirenz during this time you will need two tests.

Firstly, it is important that you receive early ultrasound evaluation. You will also have another test called maternal alpha foetoprotein test. This is a screening test for neural tube defects.

After the first trimester, there may be no point in stopping efavirenz if you are doing well on it. Sometimes it may even be a good option to use after a late diagnosis if you have a higher CD4 and nevirapine is not recommended.

The liquid formulation of amprenavir, a less commonly used protease inhibitor, is also not recommended in pregnancy (or for children under four). This is because pregnant women and young children are unable to break down one of its components called propylene glycol. The capsule form of amprenavir does not contain propylene glycol.

ddl is not recommended in pregnancy. There may be a small increased risk of birth defects with this drug. Also there is a mild possible increase with nelfinavir. These drugs are rarely used in the UK now.

There is also a strong warning to avoid using the drugs ddl and d4T together in pregnancy. There have been several reports of deaths in pregnancy in women using both these drugs together.

d4T (stavudine) is no longer recommended in the UK, except as a last resort.

And, as we described earlier, nevirapine is not recommended for women with higher CD4 counts (above 250).

### **Should I expect more side effects when I am pregnant?**

Approximately 80 percent of all pregnant women using HAART will experience some sort of side effects with these drugs. This is similar to the percentage of people using HIV

treatment who are not pregnant.

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

i-Base have produced a guide Avoiding and managing side effects, which can be very helpful for anyone using HIV-treatment. The sections in this booklet about getting on with your doctor can also be helpful whether or not you are on treatment.

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 treatment or pregnancy is the cause.

Many HIV medicines 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.

Tips to reduce nausea, and help with adherence are included on pages 52-53.

If your morning sickness is bad your doctor may prescribe anti nausea drugs (antiemetics), which are safe to use in pregnancy.

You may feel more tired than usual.

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

All pregnant women are at risk of developing a high blood sugar (hyperglycemia) and diabetes during pregnancy.

Women taking protease inhibitors in pregnancy may have a higher risk of this common complication. So, you should be sure to have your glucose levels closely monitored and be screened for diabetes during pregnancy. This is routine for all pregnant women.

Outside of pregnancy, protease inhibitors have been associated with increased levels of bilirubin.

While this is usually a measure of the health of your liver this is not always the case as with the the protease inhibitor atazanavir. Here bilirubin levels can be very high but without causing any problems.

The levels of bilirubin in the baby may also be higher than normal and your healthcare team will follow your baby's bilirubin levels very carefully and may give the baby phototherapy to reduce the levels of bilirubin.

Although extremely high levels of bilirubin may damage a baby's developing brain there have not been any reports of this occurring with atazanavir.

In the UK over 150 mothers have taken atazanavir in pregnancy and it appears to be fairly safe for mothers and their babies.

Pregnancy may be an additional risk factor for raised levels of lactic acid.

Your liver normally regulates this. Lactic acidosis is a rare but dangerous and potentially fatal side effect of nucleoside analogues.

Using d4T and ddl together in pregnancy appears to be particularly risky for lactic acidosis.

This combination is now not recommended in the UK. Consequently the risk of lactic acidosis is now extremely low.

## Resistance, monitoring and other tests



### What about resistance?

Drug resistance is an important issue during pregnancy.

If you are already using combination therapy and your viral load is not undetectable, it is important that you look at why this is occurring with an expert. This is very important for your own and your baby's health.

Resistance can develop when your viral load is detectable. This might affect your long-term health by reducing your treatment options later on. Viral load at time of delivery is also strongly linked with risk of transmission to your baby.

Taking a treatment break, if not managed properly, can lead to resistance.

Not taking all your pills at the right time can also lead to resistance.

We explain resistance and how to avoid it, and include advice on adherence in the i-Base booklet *Introduction to Combination Therapy*.

### Should I have a resistance test?

Current British pregnancy guidelines recommend a resistance test if you are changing therapy. These guidelines are the same as for a non-pregnant adult. They also recommend a resistance test if you have just been diagnosed and if you are just starting therapy for the first time.

Women stopping HAART should have a resistance test on their first viral load after they stop treatment, ideally within 6 weeks.

Women taking AZT monotherapy should have a resistance test on the viral load sample taken at delivery.

A resistance test is important to determine whether all the drugs in your combination will be active and working (both during pregnancy and in the future). It should be able to tell whether you were infected with resistant virus.

You should check that your doctor has included this test.

## Will I need extra tests and monitoring?

Both pregnancy and HIV care require good monitoring.

For HIV you will have your viral load and CD4 carefully monitored. You may also need a resistance test.

Some doctors may recommend TDM (therapeutic drug monitoring). TDM uses blood tests to check whether you are absorbing the correct amount of a drug. Drug levels, particularly of protease inhibitors can vary greatly between individuals and tend to be lower during pregnancy. Occasionally this can lead to a dose adjustment.

In addition to your HIV care you will be screened for hepatitis, syphilis and other sexually transmitted diseases, anaemia and tuberculosis (TB). Sexually transmitted diseases and vaginal infections can increase HIV transmission.

You may also need to be screened for toxoplasmosis and cytomegalovirus (CMV). These are two common infections that can be transmitted to your baby. The tests should be performed as early as possible in your pregnancy. You should be treated for these if necessary.

Your clinic will provide a thorough gynaecological check up. This will include a cervical (Pap) smear, which is particularly important if your CD4 is below 200 cells/mm<sup>3</sup>.

Otherwise, tests will be fairly routine, and may vary slightly from doctor to doctor. Routine tests include blood pressure, weight and blood and urine tests.

Unless you need extra care you will probably visit your clinic monthly for most of your pregnancy and every two weeks after the eighth month.

## Are there any tests that I should not have?

Some tests and procedures commonly used to evaluate mothers and developing babies carry a theoretical risk of increased HIV transmission.

However, this risk has not been clearly demonstrated in a study of women taking combination therapy.

HIV positive pregnant women are generally advised to avoid the following tests unless they are essential:

- Foetal scalp sampling
- Cordocentesis
- Percutaneous umbilical cord sampling
- Internal foetal labour monitoring (external ultrasound and foetal monitoring are okay)



If amniocentesis or chorionicvillus sampling are essential then covering the procedure with anti-HIV drugs is recommended.

Your healthcare team can explain what these tests are and why it is not recommended to have them.

### **OI prevention and treatment during pregnancy**

Treatment and prophylaxis for most OIs during pregnancy is broadly 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, and as your immune system recovers using HAART.

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

Prophylaxis and treatment of pneumocystis jiroveci pneumonia (PCP), mycobacterium avium complex (MAC) and tuberculosis (TB) infections are recommended if necessary during pregnancy.

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

### **Vaccine use while pregnant**

Pregnant women are at an increased risk for flu and should be vaccinated regardless of whether they are HIV positive or negative. They should be given the flu vaccine (containing season and H1N1 vaccines).

Hepatitis B and pneumococcal vaccines may be used during pregnancy.

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

### **Treating recurrent genital herpes during pregnancy**

Many women with HIV also have genital herpes. HIV positive mothers are far more likely to experience an outbreak of herpes during labour than negative mothers. To reduce this risk, prophylaxis treatment for herpes with acyclovir is often recommended.

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

Prophylaxis and treatment with acyclovir is safe to use during pregnancy.

### **How easy is it to transmit hepatitis C from mother to baby?**

If you are coinfecting with hepatitis C virus (HCV) and HIV—you may discover this through routine screening in pregnancy—there is a risk of transmission of HCV of up to 15 percent. Treating your HIV will reduce this risk of transmitting HCV.

BHIVA guidelines recommend a planned Caesarean section delivery for those who are coinfecting.

### **What about hepatitis B?**

It is very likely that mothers with active hepatitis B virus (HBV) will transmit to their babies (90 percent). Immunising the baby against HBV shortly after he or she is born can prevent transmission of hepatitis B.

This is standard practice in the UK.

It may be appropriate for the mother's combination to include HIV drugs that also work against HBV, in particular 3TC or FTC and tenofovir.

### **HIV and TB coinfection**

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

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

Most TB first line TB drugs are safe to use in pregnancy.

However, the TB drug streptomycin is not recommended in pregnancy as it can cause permanent deafness in the baby.

This drug is now only rarely used in the treatment of TB in the UK.

## 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 unknown effects to the baby.

It is difficult to know if there are any long-term effects.

Children first exposed to combination therapy are not likely to be much older than 15 now.

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

All children born to HIV positive women in the UK (and many other countries) are also being monitored. This close monitoring will provide important safety information in the future.

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

### Will HIV drugs affect the baby?

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

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

### Prematurity

Several studies show a greater risk of prematurity (baby born at less than 37 weeks) and low birth weight for babies born to mothers taking anti-HIV treatment with three or more drugs.

A recent British study found an overall rate of 13 percent (normally the rate here is about 6-8 percent).

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 important to be aware of the risks though, 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 these drugs in pregnancy. The only caution at the moment is possibly with the two drugs ddI and nelfinavir, neither of which is recommended in pregnancy in the UK.

### **What about mitochondrial toxicity?**

Mitochondria are the “energy producing factories” within our cells. There have been a small number of reports that the use of 3TC and AZT in pregnancy may be linked to mitochondrial damage in children.

In a large study from America, medical records of over 20,000 HIV negative children born to HIV positive mothers were searched for abnormalities associated with mitochondrial damage. The study was designed after reports from France of two deaths of infants exposed to AZT and 3TC and six other cases of mitochondrial toxicity.

This large study failed to show evidence of fatal mitochondrial damage in children exposed to these drugs during their mothers' pregnancy. This was very reassuring.

In a rare number of cases though, short-term mitochondrial toxicity can be a problem in newborn babies. A

very small number of babies have been reported with severe lactic acidosis and anaemia believed to be linked to anti-HIV drugs. All have recovered with appropriate care.

Some studies have suggested that these mitochondrial damage effects are not seen when these drugs are used in HAART.

### **What about anaemia?**

Anaemia has been reported in babies born to mothers on HIV medications but this passes quickly and rarely requires a transfusion.

### **Will my baby be monitored for these symptoms?**

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

## Choices for delivery



The way your baby is born—whether you choose to have a vaginal birth or pre-labour Caesarean section is an important consideration for HIV positive women.

If you do have a Caesarean section, the operation must be carried out before the onset of labour and ruptured membranes. This is called “pre-labour” “elective” or “scheduled” Caesarean section.

Several early studies showed that pre-labour Caesarean section significantly reduced mother-to-child transmission compared to vaginal birth. But these studies were before combination therapy and viral load testing were routinely used.

Data from the UK and Ireland indicate that mothers on combination therapy with an undetectable viral load can deliver vaginally and that pre-labour Caesarean delivery does not offer any additional benefit to the babies.

### Should I have a pre-labour Caesarean section?

If you do not need treatment for your own health and choose to use AZT alone, a pre-labour Caesarean section will be necessary to reduce transmission risk to minimal levels. If a woman’s viral load is undetectable on HAART, there is such a low risk of transmission associated with either mode of delivery that no advantage in transmission risk occurs through pre-labour Caesarean.

If your viral load is detectable, greater than 50 copies/mL, a pre-labour Caesarean is recommended, especially if your viral load was undetectable and has become detectable.

### **What strategy is recommended?**

Current British guidelines say: "Mode of delivery must be discussed with the woman and her wishes taken into account."

A choice of either Caesarean section or vaginal birth is offered when a mother's viral load is below detection on combination therapy.

If you have a high CD4 count and low viral load and choose to receive AZT, you will have the pre-labour Caesarean section at 38 weeks. If your viral load is undetectable on treatment and you choose to have a pre-labour Caesarean section, you will have it at 39-40 weeks.

### **What is the likelihood of complications?**

Caesarean section is major surgery. Therefore some complications—particularly the risk of infections—are slightly more common in women having Caesarean sections than women having vaginal delivery.

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

A pre-labour Caesarean section will not offer protection to your baby if you go into labour earlier than expected.

If your waters break before your Caesarean section is due your medical team will consider managing you as though you had presented late in pregnancy with an emergency Caesarean section and additional anti-HIV therapy.

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

If you have a Caesarean section now, having a natural birth in the future is more complicated and difficult.

This is an important consideration.

You may be offered the choice of vaginal delivery but you will be more likely to need a Caesarean section than a woman who has previously delivered vaginally.

This is important to know if you plan to have more children in a country where planned Caesarean section is not possible, safe or easily available and there is less access to obstetric care.

### **How do I make a decision?**

If you have an undetectable viral load and have a choice, before making the choice, it is important that you are informed of the risks and benefits associated with each mode of delivery. You should spend time discussing any concerns that you have with either mode of delivery with your healthcare team.

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

### **What else do I need to remember for the birth?**

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

Include pyjamas or something to wear in hospital, a toothbrush, wash bag—and of course your ARV drugs. Remember to bring them with you even if you are not sure that you are in labour.

It is important that you remember to take all your drugs on time as usual, including the day of delivery or planned pre-labour Caesarean section. This is a critically important time to make sure that you don't miss any doses.

Remembering to do so can be difficult with everything going on, particularly if you are waiting for a long time.

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

### **Caesarean section**

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.

It is important to understand that if your HIV is well managed and your viral load is below detection on combination therapy, then the risk of transmission with either mode of delivery is practically zero.

If you are receiving treatment and do choose to have a vaginal birth there is still a possibility that you may need to have an emergency Caesarean section for obstetric reasons. This can also happen to any woman having a vaginal delivery whether she is HIV positive or negative.

Medical teams will be a bit more cautious though with an HIV positive woman than an HIV negative woman with vaginal delivery.

## After the baby is born

### What will I need to consider for my own health?

Adherence! This means taking your drugs exactly as prescribed.

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

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

Babies born to HIV positive mothers will always test HIV positive at first if the usual antibody tests are used.

This is because they share their mum's antibodies. If your baby is not infected with HIV these will gradually disappear. This can sometimes take as long as 18 months.

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

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

If all these tests are negative, and you are not breastfeeding your baby, then your baby is not HIV positive.



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

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

Your baby will need to take HIV drugs for four weeks following his or her birth.

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

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

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

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

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

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

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



### **To check the baby is HIV-negative**

HIV PCR DNA – a polymerase chain reaction (PCR) test is a highly sensitive test that detects tiny amounts of HIV DNA in blood plasma.

The test will “amplify” or multiply HIV DNA in the test tube so that it can be more easily detected.

## Feeding your baby

There is a risk of transmitting HIV from mother-to-baby via breast milk.

HIV positive mothers living in industrialised countries can easily avoid this by using bottles and infant formula milk.

### **Bottle-feeding and free formula milk**

Avoiding breastfeeding is currently strongly recommended for all HIV positive mothers in the UK, regardless of their CD4, viral load or treatment.

After doing all the right things during pregnancy and delivery, you will not want to risk your baby's health now by breastfeeding.

Mother to child transmission of HIV is now very low in the UK. Alongside using antiretrovirals in pregnancy and a carefully managed delivery, exclusive feeding with infant formula milk has contributed to our excellent low rates.

All HIV positive mothers in the UK should be supported to formula feed their babies. This means that, if you cannot afford the formula, bottles and sterilising equipment, these should be provided by your hospital so that you do not need to breastfeed. Schemes vary from clinic to clinic.

Your midwife should discuss whether you need this extra support as part of your discharge package when you leave the hospital with your baby.

Medical treatment and provision of formula milk will be in confidence. Please make sure that you take advantage of this if you need to.

### **Can I breastfeed occasionally?**

It is very strongly recommended that you do not breastfeed occasionally.

In fact, several studies showed that "mixed feeding" may carry an even higher transmission risk than if you breastfeed exclusively.

### **Sometimes people ask me why I do not breastfeed**

Sometimes mothers can be worried that being seen to be bottle-feeding will identify them as HIV positive.

It is up to you whether or not you tell anyone that you are HIV positive.

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

For example, you can say you have cracked nipples or that the milk didn't come, both of which are common.

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

How does the cost of formula milk for a year compare to the cost of HIV treatment for life?

As an HIV positive mother, I would never put my baby at even the slightest risk of contracting HIV through my breast milk as I live in the UK where I can access clean water and formula milk.

Mem, London

### Breastfeeding

The World Health Organisation (WHO) recently issued new infant feeding guidelines for women in countries where replacement feeding is not safe or available.

Breastfeeding is safer if the mother or the baby receives ARVs.

The British HIV Association (BHIVA) and the Children's HIV Association (CHIVA) recommend the complete avoidance of breast feeding for HIV-positive mothers, regardless of whether the mother is healthy, has an undetectable viral load or on treatment.

The BHIVA/CHIVA position statement on infant feeding in the UK can be accessed here:

<http://www.bhiva.org/BHIVA-CHIVA-PositionStatement.aspx>

Many community groups in the UK (including i-Base, Positively UK and the UKCAB) also recommend complete avoidance of breastfeeding for HIV-positive mothers.

Further reading:

<http://www.positivelyuk.org/policy.php>

## Tips to help adherence

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

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

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

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

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

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

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

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

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

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

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

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



### Tips to help with morning sickness or drug-associated nausea

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









## Feedback

Your feedback on this guide helps us develop new resources and improve this resource. All comments are appreciated. Comments can be posted free to:

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Too easy     Easy     Difficult     Too difficult

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