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Guide to HIV, Pregnancy and Women's Health

Introduction
Mother's health is best for baby
Planning a pregnancy
Prenatal care
Choices for delivery
After baby is born

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Introduction to Combination Therapy
Guide to Changing Treatment
Guide to Avoiding & Managing Side Effects
Guide to HIV and Hepatitis Coinfection
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HIV i-Base Guide to HIV, Pregnancy and Women's Health

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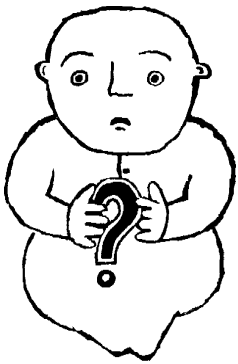


This is the fourth edition of the i-Base pregnancy guide. Since the last edition there has been an update of the pregnancy guidelines issued by the British HIV Association (BHIVA), and these changes have been reflected in our guide.

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 one in a thousand 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.

The similarly low transmission rate seen in selected women with very low viral load who chose to receive AZT monotherapy and deliver by planned Caesarean section is important too, as it confirms that this remains an option.

We will explain what all these options mean and when they are appropriate in our guide.

We have also included important new information for couples where one partner is HIV-positive and the other is HIV-negative. This is based on the Swiss Statement, which suggests that by using HIV treatment to reduce viral load to undetectable the risk to the HIV-negative partner from natural conception is close to zero. But the details of the Statement are important - see page 23.

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/cms1221368.asp

Background and general questions

This booklet aims to help you get the most out of your own HIV 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 for the health of your baby.

If you have just been diagnosed with HIV

You may be reading this booklet 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 booklet, you may have never before known or read anything about HIV. As you will see, 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 sources of information to help you. Some useful contact details are included on pages 10-11.

The advice that you receive from these sources and others may be different than 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.

Can HIV-positive women become mothers?

Yes, with HIV treatment. Women around the world have safely used antiretroviral drugs in pregnancy now for over 10 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% of babies born to HIV-positive women will be born HIV-positive. One in four is not good odds, though, especially because modern

- **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.

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. 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. (See page 44)

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

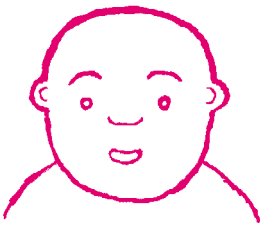
So, as with treatment for anyone with HIV, one important goal of therapy is to reach an undetectable viral load. This is particularly important at the time of delivery. The time between

- **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 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 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 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.
- 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.



when your waters break and the actual delivery is also a risk factor for transmission. This period is called "duration of ruptured membranes".

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.

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 six weeks after birth. This reduced the risk of the baby becoming HIV-positive from 25% to 8%.

After 1994, this strategy was recommended for all HIV-positive pregnant women. Even further advances have been made over the last few years, especially since combination therapy became more common the late 1990s. Transmission rates with combination therapy are now less than 1%.

AZT is still the only drug licensed for use in pregnancy. There is also a lot of experience of using it. Many doctors still prefer to include it in a woman's combination if she is pregnant. However, if you have resistance to AZT, you should not use this drug. Other reasons some women do not use AZT might be that they find the drug's side effects very difficult to manage or that they are already on an effective, stable combination that does not contain AZT.

In these cases, it is OK to use a combination without AZT. Transmission rates of mothers using combinations without AZT are similar to those that contain AZT. 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, using combination therapy for pregnant women is still at a relatively early stage. Many aspects of its use are still unproven. 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.

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 HIV-negative births.

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

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

- **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 (mm3) 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/mm3. Some factors, such as being tired, ill or pregnant, can cause temporary drops in a person's CD4 count.
- A CD4 count below 200 cells/mm3 is considered to be low, and nearly all treatment guidelines recommend starting treatment before the count reaches that level. You are more vulnerable to infection if you have a CD4 count below 200 cells/mm3.

- **Prenatal** refers to the period before a baby's birth, the time in which the foetus (developing baby) grows in the uterus.
- **Opportunistic infections (OIs)** are infections that can cause serious illnesses in people with low CD4 counts, as is the case with many HIV-positive people. OIs usually do not occur in people with healthy immune systems.

  Examples of OIs that occur in HIV-positive people (generally when they are not using combination therapy) are PCP (pneumocystis pneumonia), CMV (cytomegalovirus) and MAC (Mycobacterium Avium Complex) - see page 35.

access to an international birth defect registry. This has tracked birth defects in babies exposed to antiretroviral drugs since 1989. The registry can be found at the following website:

http://www.apregistry.com

So far, the registry has only seen a small increase in the type or rate of birth defects, compared to the babies born to mums not using HIV drugs, for the drug ddI.

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/mm3, 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, however, if your CD4 falls below 200 cells/mm3. Below this level, you are at a higher risk from opportunistic infections (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 many 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 the 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

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 still may be unfamiliar or confusing, including CD4, viral load and resistance.

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

http://www.i-Base.info

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 p.m. on Monday, Tuesday and Wednesday.

We also offer an information service by e-mail from:

info@i-Base.org.uk

i-Base can answer your questions by email or online:

questions@i-Base.org.uk

www.i-base.info/questions

Other useful contact information

Body and Soul

Telephone: 020 7383 7678

www.bodyandsoul.demon.co.uk

Positively Women

Telephone: 020 7713 1020

www.positivelywomen.org.uk

International Community of Women (ICW)

www.icw.org

British pregnancy and treatment guidelines

www.bhiva.org/

U.S. pregnancy and treatment guidelines

www.aidsinfo.nih.gov/guidelines/

Your clinic should have a list of local support services.

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.

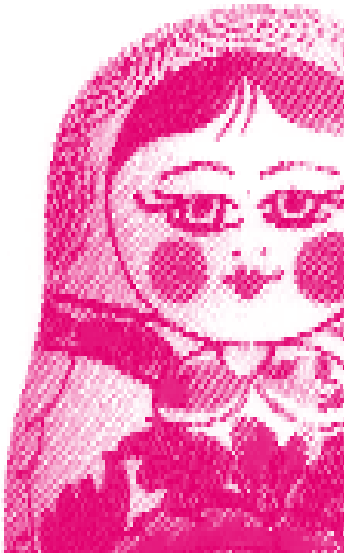
Sometimes medical research can forget the fact that HIV-positive pregnant women are people who need care for their own HIV infection. This can sometimes be neglected or forgotten by mothers and healthcare workers when the baby's health is the main focus. You should not forget this, though: your health and care are very important.

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

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; 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



Principles of care

- The mother should be able to make her own choices about how to manage the 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 nonjudgemental.
- 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.

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

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. We will look at 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 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. 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.

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 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

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 micro-transfusion may occur.

Scientists know that transmission occurs during delivery because:

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

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

Breastfeeding

Doctors think that HIV in breastmilk 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. (See page 44)

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; and
- treat any sexually transmitted infections.

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

It is reassuring to know that over 1000 HIV-positive pregnant women had uninfected babies in the UK in 2006.

- 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 you should 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.

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 sero-different (the medical term is sero-discordant) couples. (These are terms for when one partner is HIV-positive and the other HIV-negative.)

It is usually unwise for sero-different couples to have unsafe sex. Even when politely called a "conception attempt", there is always a risk to the HIV-negative partner of contracting HIV.

For an HIV-negative woman, for example, 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 viral load is undetectable in seminal fluid.

For an HIV-negative man, transmission risk depends on the level of viral load in the genital fluids 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 is of greater risk to an HIV-negative woman than sex with a circumcised man.

Infections of the genital tract also increase the risk of sexual transmission of HIV. Regardless of the method of conception, both members of a sero-different couple should check for such infections. This should include screening and treatment for other sexually transmitted infections. The man should have a semen analysis. This can rule out any infection and also to ensure that his sperm count is fit and healthy.

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 (we talk about this and how to make it safest below). But there is still a risk involved for both male and female negative 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, 4% of women became HIV-positive. But this study took place before the routine use of HAART.

A more recent study in Spain of 40 sero-different couples conceiving when the man was on HAART and had a viral load of less than 50copies/mL for at least 6 months, had no transmissions.

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.

For those who wish to conceive, the options are discussed on the next pages.

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 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.

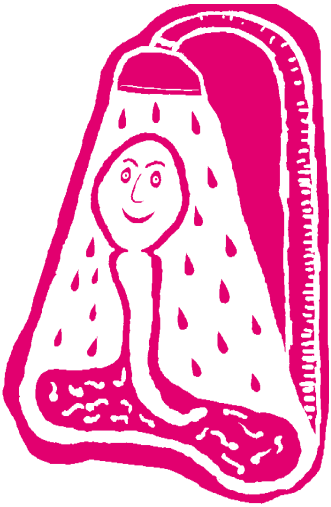
This is therefore the safest way for an HIV-negative woman to become pregnant from an HIV-positive man.

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.

Unfortunately, it is not always possible to obtain this procedure on the NHS, but recently, in some cases people were funded as part of a risk reduction intervention at this clinic.

HIV-prevention or risk reduction funds rather than fertility treatment budgets may therefore be easier to access for sperm washing. Some cycles at Chelsea and Westminster have received NHS funding on a risk reduction basis following a letter of recommendation by the GU doctor to the couple's health authority.



Cost can be a barrier for many to these services and health authorities must address this issue.

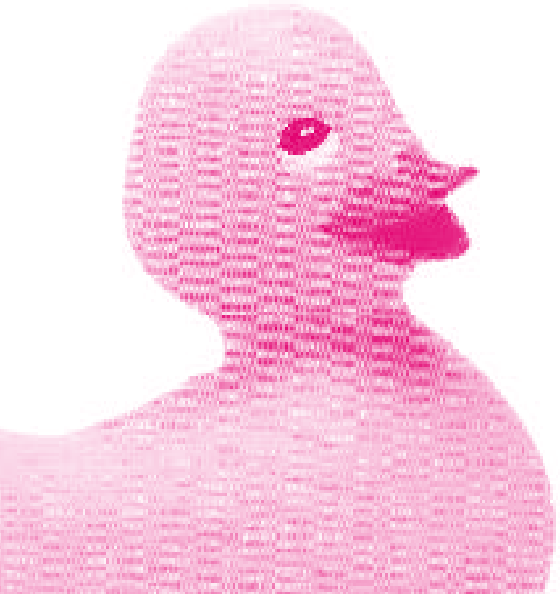
The Chelsea and Westminster assisted conception unit can be contacted on 0208 746 8585.

As we said 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 both in blood and semen for at least 6 months. Conception can either be naturally (having gentle sex) or with self insemination. Most doctors can provide guidance on how to plan and identify which days would be appropriate.

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 10% of people with undetectable levels in blood, can have detectable levels in semen, so this could offer additional safety.



Artificial or self-insemination (see below) 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.

This is more controversial because there is still a small risk of transmitting HIV. However, especially where sperm-washing is not available, there have been encouraging reports (like the Spanish study of 60 couples) that this has been successful. 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 from the woman using 1-2 days of HIV-drugs 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 can be 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.

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 serodiscordant 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 cirumstances would be unlikely to lead to HIV infection in the HIV-negative partner. They were not recomending 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 fullfilled the above criteria.

If you want to read more about The Swiss Statement:

http://www.aids.ch/e/fragen/pdf/swissguidelinesART.pdf

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 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, most doctors still recommend safer sex. This is to limit the possibility of re-infection with a different strain of HIV. However re-infection is only a risk if one partner has drug resistance or a different type of HIV.

It is likely that the risk is low, but it is possible. 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 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, especailly 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 sero-different couples.

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 it 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 just as 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. If you do, then you can and should complain about this.

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

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 booklet. 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 should strongly consider treatment during pregnancy, even if it is only used for a short time or just at the end of the pregnancy and stopped after the baby is born. This is regardless of the mother's CD4 or viral load counts.

"Treat as non-pregnant adult" is advice generally given when caring for HIV-positive pregnant women who need treatment. However, treatment recommendations for pregnant women are slightly different than those for other HIV-positive adults.

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

'Treat as non-pregnant adult'

- This is a very commonly used phrase in HIV and pregnancy. This means that generally your HIV is treated as if you were not pregnant.
- There are some exceptions—particularly when you do not need treatment for your own HIV and concerning some of the commonly used HIV drugs.

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

UK guidelines recommend starting treatment while your CD4 count is about 350 cells/mm3. Treatment is not usually 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% in untreated women to less than 1% in women treated with anti-HIV drugs.)

As a result, treatment is offered to all HIV-positive pregnant women, even those with CD4 counts over 350 cells/mm3 who have never been on treatment before.

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

1. 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 C-section at 38-39 weeks or a vaginal birth.

2. Use AZT three-part monotherapy (as in the 076 study) and have a planned pre-labour C-section at 38 weeks.

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.

Benefits of AZT/C-section:

- The risk of transmission is also low (less than 1%)
- You will use fewer drugs

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

Risks of AZT/C-section:

- Caesarean sections are major surgery and can carry additional risks for the mother.
- A very low risk of developing resistance to AZT

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.

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

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. As mentioned earlier, this can be a very difficult time practically and emotionally. Ask for extra support if you need it.

Guidelines currently recommend that all HIV-positive people with CD4 counts under 350 cells/mm3 should be on treatment, including pregnant women. Treatment will also depend on when in your pregnancy you are diagnosed with HIV.

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. But some women and their doctors may still prefer to delay treatment.

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. But 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 being sick, 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, your doctor will recommend it.

What if I discover I am HIV-positive late in pregnancy?

Even late in pregnancy, there is still a benefit to using treatment. Even after 36 weeks, it can reduce your viral load to very low levels.

Treatment for one week with combination therapy can reduce your viral load very quickly by a large amount and some anti-HIV drugs 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.

See also pages 28-29: "Which drugs should I use?"

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

It is likely you will be recommended to use AZT as part of your combination.

This is because AZT is still the only HIV drug licensed for use in pregnancy. You should have a resistance test to confirm whether AZT is active against your own HIV. This test will help decide which other drugs you need to use.

If you do not need to use treatment for your own health, you may decide to use "START" (see page 25). You will probably be recommended to use AZT plus 3TC as two of the drugs as there is a lot of data on them regarding pregnancy (see the box on page 32).

However, because 3TC resistance develops very easily it you should not just use these two drugs alone. You should use them with another HIV drug in a triple combination. This third drug will probably be a protease inhibitor. Again, the resistance test will help ensure that you choose drugs that will work.

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

If you plan to stop treatment straight after your baby is born a protease inhibitor has another advantage. Your body processes protease inhibitors relatively quickly. If you are taking it with AZT and 3TC, you can stop all your treatments at the same time with a low risk of resistance.

Another drug that is often used is an NNRTI called nevirapine, which is a drug that has been widely used in pregnancy.

There is however a caution against the use of nevirapine for women with CD4 counts above 250 cells/mm3 because of a risk of liver (hepatic) toxicity.

Nevirapine appears to be safe for women with lower CD4 counts (below 250 cells/mm3). 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/mm3.

If you are already using combination therapy, you are likely to remain on the same combination. 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. See the section about which drugs are not recommended for pregnancy, on page 30.

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 this triple combination until your viral load is below 50 copies/ml. This will reduce the risk of resistance. If your CD4 count is less than 250 cells/mm3 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 250 cells/mm3 you will be advised to continue HIV treatment but should you choose to stop treatment, you will need to stop the nevirapine before the other two drugs.

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 recommended in pregnancy. This drug caused brain damage in the developing foetus in a single animal study. So far there are no reports of a similar increased risk of in human babies. But, if other treatment options are available, there is a strong caution against its use. This is 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.

ddI is not recommended in pregnancy as there is a small increased risk of birth defects with this drug.

There is also a strong warning to avoid using the drugs ddI and d4T together in pregnancy. There have been several reports of fatal side effects in pregnant women using both these drugs together. d4T is no longer recommended for first-line therapy in the UK guidelines.

As we described earlier, nevirapine is not recommended for women with higher CD4 counts (above 250mm3).

Should I expect more side effects when I am pregnant?

Approximately 80% 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 has produced a 36-page

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. Some tips to reduce nausea, and to help with adherence, are included on pages 46.

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 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. This is a measure of the health of your liver.

This is a side effect of the protease inhibitor atazanavir. There is not yet very much experience of using this drug in pregnancy but so far it seems to be fairly safe. Your healthcare team will follow you and your baby's bilirubin levels very carefully. This is because extremely high levels of neonatal levels may damage a baby's developing brain.

A report from the UK of 33 pregnancies of mothers using atazanavir did not show seriously high bilirubin levels in mothers or in 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 ddI together in pregnancy appears to be particularly risky for lactic acidosis. This combination is now not recommended in pregnancy.

Please check the i-Base side booklet Avoiding and Managing Side Effects for more details on symptoms and monitoring.

Preclinical 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.

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

Nucleoside analogues (NRTIs or nukes) are one type of HIV drug and include AZT, ddI, 3TC, abacavir and tenofovir (a nucleotide). Usually a first HIV combination will include two of these drugs and either a non-nucleoside reverse transcriptase inhibitor (NNRTI) or a protease inhibitor (PI).

Non-nucleoside reverse transcriptase inhibitors (NNRTIs) and **protease inhibitors (PIs)** are both types (or classes or families) of antiretrovirals that control the virus in different ways, both to each other and to NRTIs. So in addition to two nukes, triple therapy will generally contain either an NNRTI or a PI.

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.

Using only one drug (monotherapy) or two drugs (dual therapy) are not good options as the minimum treatment for an HIV-positive person. Therefore, neither of these should be used for HIV-positive women who are pregnant and require treatment for their own HIV. Of strategies for pregnant women who do not require treatment, AZT used alone is less likely to induce resistance than AZT plus 3TC or nevirapine alone.

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 will affect your long-term health. 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.

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

We explain drug 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 vary greatly between individuals and tend to be lower during pregnancy.

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/mm3. 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
- cordocentis
- percutaneous umbilical cord sampling
- internal foetal labour monitoring (external ultrasound and foetal monitoring are perfectly OK)

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.

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

Mono and dual therapy. Monotherapy is using only one HIV drug and dual therapy uses two drugs. Neither strategy has been as effective as using three drugs for treating HIV. In some circumstances though, AZT monotherapy is still recommended for reducing mother-to-child transmission.

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

Vaccine use while pregnant

Hepatitis B, flu and pneumococcal vaccines may be used during pregnancy. They should only be used after your viral load has become undetectable with combination therapy, however, because there is a temporary increase in viral load after vaccination.

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

Treating recurrent genital herpes during pregnancy

A large number (about 75%) of 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

HIV and hepatitis coinfection

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

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

BHIVA guidelines recommend a planned C-section delivery for those who are co-infected.

What about hepatitis B?

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

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

HIV and TB co-infection

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 . 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 about unknown effects to the baby.

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

Today, even children who were first exposed to AZT monotherapy during their mothers' pregnancy are not older than teenagers.

Children first exposed to combination therapy are not likely to be much older than 10 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, although overall the drugs do seem reasonably safe.

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

Prematurity

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

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

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 with the drug ddI, which is not usually 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.

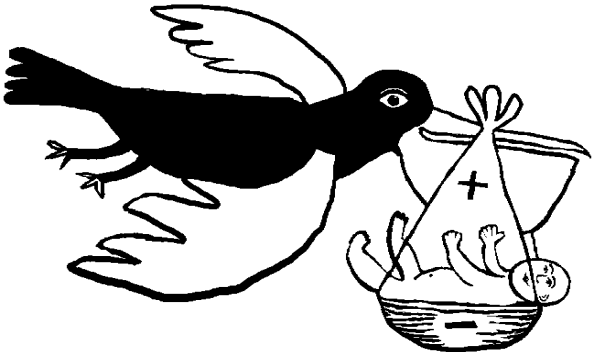
What about anaemia?

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 and use of Caesarean section



The way your baby is born—whether you choose to have a vaginal birth or Caesarean section (C-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" C-section.

Several early studies showed that pre-labour C-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. Recent 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 C-section?

If you do not need treatment for your own health and choose to use AZT alone, a pre-labour C-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.

HIV transmission to the baby is uncommon among mothers who are taking HAART, even when their viral load is greater than 50 copies/mL but in the UK pre-labour Caesarean is

indicated, especially if the 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 C-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 C-section at 38weeks. If your viral load is undetectable on treatment and you choose to have a pre-labour C-section, you will have it at 39-40 weeks.

What is the likelihood of complications?

As mentioned earlier, C-section is major surgery. Therefore some complications—particularly the risk of infections—are slightly more common in women having C-sections than women having vaginal delivery.

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

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

Will a C-section now stop me having a natural birth in the future?

This is a very important consideration. If you use a C-section now, having a natural birth in the future is more complicated and difficult. You may be offered the choice of vaginal delivery but you will be more likely to need a C-section than a woman who has previously delivered vaginally. Once a woman has given birth by C-section it is usually recommended that she uses C-section for future babies. This is important to know if you plan to have more children in a country where elective C-section is not possible, safe or easily available.

How do I make a decision?

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

Caesarean or **C-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 C-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.

Before making a choice, though, 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 is below 50 copies/ml. This is not only for the risk of transmission but 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 anti-HIV drugs.

It is very important that you remember to take all your drugs on time as usual, including the day of delivery or planned pre-labour C-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.

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.

On pages 47-50 are charts to help you and your baby in the first 6 weeks.

The i-Base booklet Introduction to Combination Therapy has tips to help you with adherence.

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

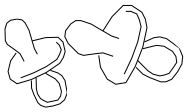
Babies born to HIV-positive mothers will always test HIV-positive at first if the usual antibody tests are used. This is because they share their mum's antibodies. If your baby is not infected with HIV these will gradually disappear. This can sometimes take as long as 18 months.

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 one month 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 probably four to six 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 are resistant to AZT.

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 began using anti-HIV drugs in pregnancy. This is because some HIV drugs 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: risks and options

There is also 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 formula milk.

Bottle-feeding and free formula milk

Bottle-feeding is currently strongly recommended for all HIV-positive mothers.

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

If you cannot afford the formula, bottles and sterilising equipment can be provided by your hospital so that you do not need to breastfeed. But 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. None of the people who work at the hospital or support workers will have any connection whatsoever with the immigration department.

Can I breastfeed occasionally?

It is very strongly recommended that you do not breastfeed occasionally. In fact, one study 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

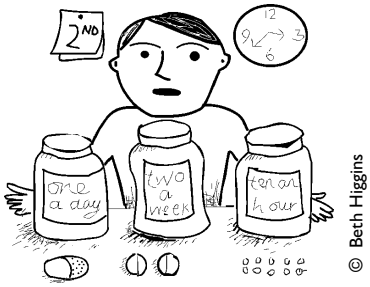
Sometimes mothers can be worried that being seen to be bottle-feeding will identify them as HIV-positive.

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 bottlefeeding. 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.

Tips from other i-Base guides



The following tips are taken from the i-Base booklets Introduction to Combination Therapy and Guide to Avoiding and Managing Side Effects. Both guides are available free by calling 020 7407 8488.

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?

Additional tips for once you begin treatment

- Use the charts on pages 50-51 to plan your timetable. Use them to get used to the routine. For the first few weeks mark off each dose and the time that you took it. You can also use this to link your routine to your new baby's.
- 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.
- 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 is also useful. It can be taken in tea or in chewing gum.

CD4 and viral load results

These blood tests are used to monitor your health and your response to treatment.

CD4 count - This blood test checks your immune system

CD4% - This is similar to the CD4 count but is often more stable

Viral load - This test measures the amount of HIV in a sample of blood. It is used to decide when you need to start treatment, and whether the treatment is working effectively.

Even rough figures are useful from your previous history and your doctor can provide you with these.

The lowest CD4 count and highest viral load results when you were first diagnosed and before you started treatment are the most important.

Date (month / year)	CD4 (cells/mm3)	CD4%	Viral load	Other notes
e.g july 00	234	14	180,000	

Antiretroviral treatment

Your choice of new and future drugs will depend on the drugs you have used in the past and the reason you stopped using them.

It is important to know whether this was because of resistance or side effects.

If you can't remember exact details, even rough dates are useful (ie taking AZT for 6 months in 1992 etc).

e.g d4T 40 mg	Feb 03	Jan 04	neuropathy

Other notes

Adherence support charts

Schedule planner: Use the top chart to plan your pill timetable with your doctor, nurse or pharmacist. Use shading to indicate when you mustn't eat if you are using ddI without tenofovir or indinavir without ritonavir; and meal times for drugs you have to take with food such as lopinavir/r (Kaletra), nelfinavir, ritonavir, saquinavir, atazanavir and tenofovir.

	AM							PM												AM		
Drug name	6	7	8	9	10	11	12	1	2	3	4	5	6	7	8	9	10	11	12	1	2	3

Adherence check:

Once you have worked out a daily regimen above use the table below to mark off each dose after taking it for the first few weeks. Write the name of the drug and the time you need to take it in the top boxes. Use a different box for each drug. Then tick off the dose and write the time you took the dose in the sections underneath. Use a photocopy, or draw a new version yourself to use for the second and third weeks or if you need a larger table. This will help you know how well you are doing and this will be helpful when you next see your doctor.

Week date: _____

	Drug names + times: AM			Drug names + times: PM		
Monday						
Tuesday						
Wednesday						
Thursday						
Friday						
Saturday						
Sunday						

0808 800 6013

i-Base treatment information phoneline

mon > tues > wed > 12.00–4pm

i-Base can also answer your questions by email or online:

questions@i-Base.org.uk

www.i-base.info/questions

i-Base publications

All i-Base publications are available free. Treatment guides are written in everyday language. HTB is written in more technical medical language. Please send me: *(please write clearly)*

- Introduction to Combination Therapy ☐
- Changing Treatment: Guide to Second-line Therapy ☐
- Avoiding & Managing Side Effects ☐
- Guide to HIV and Hepatitis C ☐
- HIV Treatment Bulletin (HTB) ☐

Publications in other languages are available in pdf format at www.i-Base.info

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