

# Guide to HIV, pregnancy & women's health December 2015



HIV i-Base  
ISSN 1475-0740  
[www.i-Base.info](http://www.i-Base.info)  
Watch for out-of-date information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 includes:

- What to do if you find out that you have HIV when you are pregnant.
- What to do if you already know you are HIV positive and decide to have a baby.
- Antiretrovirals in pregnancy, mothers' health and babies' health.
- Having an HIV negative baby if you are HIV positive.
- Safe conception using antiretrovirals for couples where one partner is positive and one is negative.

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

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

#### ABOUT HIV i-BASE

HIV i-Base is a London-based HIV treatment activist organisation. i-Base works in the United Kingdom and internationally to ensure that people living with HIV are actively engaged in their own treatment and medical care and are included in policy discussions about HIV treatment recommendations and access.

[www.i-base.info](http://www.i-base.info)

## Introduction

This is the 7th edition of the i-Base pregnancy guide. Important changes in the guide because of new research include:

- HIV treatment is now routinely recommended for everyone who is HIV positive. This includes pregnant women.
- Your CD4 count is no longer used to decide (or delay) when to start treatment. It is also no longer used to decide to stop treatment after your baby is born.
- New information about safe conception for couples where one is HIV positive and the other HIV negative. This is about being on antiretroviral therapy (ART) with an undetectable viral load.
- Starting ART as soon as possible in pregnancy. This could mean when you are diagnosed.
- A stronger recommendation for vaginal delivery. This is for mothers on ART with undetectable viral load and no other complications.

These changes are all based on the UK guidelines from British HIV Association (BHIVA). The UK is one of the safest countries in the world to have a baby. Using ART, good care, and by not breastfeeding, the risk of transmitting HIV to the baby is less than 1 in 1000. We explain what all these words and terms mean in this guide.

British HIV Association (BHIVA) and Children's HIV Association (CHIVA) Guidelines for the Management of HIV Infection in Pregnant Women (2014 update) are online at:

[www.bhiva.org/documents/Guidelines/Pregnancy/2012/BHIVA-Pregnancy-guidelines-update-2014.pdf](http://www.bhiva.org/documents/Guidelines/Pregnancy/2012/BHIVA-Pregnancy-guidelines-update-2014.pdf)

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:

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



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## Background and general questions

This guide will help you get the most out of your HIV treatment and care if you are considering pregnancy or during your pregnancy. We hope that it will be useful at all stages: before,

during and after pregnancy. It should help whether or not you are already on ART. It includes information for your own health and the health of your baby.

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 ART.

Jo, London

## If you have just been diagnosed with HIV

You might be reading this guide at a confusing time in your life. Finding out that you are pregnant or that you are HIV positive can each be overwhelming. It can be even more difficult if you find out about both at the same time.

Both pregnancy and HIV involve many new words and terms. We try to explain what these terms mean and how they might affect your life.

It is likely that even if things seem difficult now, they will get better and easier. It is 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. The advice that you receive might be different to that given to HIV negative women. This includes information on medication, caesarean section (C-section) and breastfeeding.

It is important to understand information about your health and choices. Here are some tips if it is not clear, or if you are confused or concerned:

- Ask your doctor lots of questions. If there is something in this guide you don't understand, take the booklet to your appointment. Your doctor can explain.
- Take your partner or a friend with you to your appointments.
- Talk to other HIV positive women who have had children.

## Can HIV positive women become mothers?

Yes. Women around the world have taken HIV drugs safely in pregnancy now for over 20 years. Now this usually involves taking at least three drugs and is called ART.

ART has completely changed the lives of people with HIV in every country where it is used. ART 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 ART are not just to your own health. Treating your HIV will reduce the risk of your baby becoming HIV positive to almost zero.

Without ART, one in four babies born to HIV positive women will be born HIV positive. But ART can almost completely prevent transmission of HIV.

## How is HIV transmitted to a baby?

Transmission is the word for when HIV passes from one person to another. Mother to baby transmission is also known as vertical transmission.

Most vertical transmissions happen near the time of or during labour and delivery (when the baby is being born). Vertical transmission also includes transmission through breastfeeding.

The biggest risk factor for vertical transmission is the mother's viral load. This is a measure of how much HIV is in your blood.

The main aim of ART is to get viral load to undetectable. This is the same for everyone with HIV.

Viral load tests results are in copies per millilitre (copies/mL). Undetectable viral load is when this gets to less than 50 copies/mL.

When we talk about an undetectable viral load in this guide we mean less than 50. If a mother's viral load is undetectable when her baby is born – particularly if this has been the case throughout pregnancy – the risk of vertical transmission is almost zero.

Undetectable viral load is particularly important at the time of delivery. Most risk factors for transmission are removed by reducing the amount of HIV in the blood to undetectable.

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

Some key points to remember:

- A mother's health directly relates to the HIV status of the baby.
- Having an HIV positive father 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. 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

### **Are pregnant women automatically offered HIV testing?**

HIV testing in pregnancy is now recommended in many parts of the world. In the UK, clinics must offer and recommend that all pregnant women have an HIV test.

This is part of routine antenatal care (this means “before birth”, occasionally called “prenatal” and is the care you receive before and during your pregnancy).

An HIV test in pregnancy is important. It means that women are able to look after their own health, whether or not the result is positive.

If you test positive, you can protect your own health and your baby’s.

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

Yes. Reducing the risk of a baby becoming HIV positive was an early benefit of HIV drugs. Although pregnant women are often advised against taking many medicines, this is not the case with HIV drugs.

Thousands of women have taken these drugs all over the world without any complications. This has resulted in many healthy HIV negative babies.

You and your doctor will talk about your treatment during your antenatal discussions.

Your healthcare team has access to an international birth defect registry. This has tracked birth defects in babies exposed to antiretroviral drugs for over 25 years. The reports are online:

[www.apregistry.com](http://www.apregistry.com)



This registry has not seen any increase in the type or rate of birth defects in babies whose mothers have been treated with currently used ART. These rates are similar to those for babies born to mothers who did not take these 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. ART has fulfilled my dreams of becoming a mother again.

Jenny, London

### Will being pregnant make my HIV worse?

Pregnancy does not make your HIV get worse.

But being pregnant might cause your CD4 count to drop a little. CD4 count is the test that shows whether HIV has damaged your immune system.

The CD4 drop in pregnancy can vary but it is usually about 50 cells. It is not a real reduction in CD4 cells but the same amount in a larger amount of blood (the amount of blood increases when you are pregnant).

The drop is only temporary. Your CD4 count will generally return to your pre-pregnancy level soon after the baby is born.

Sometimes if you start taking ART in pregnancy your CD4 count might 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 ART.

HIV also does not affect the health of the baby during pregnancy, unless the mother develops an opportunistic infection.

## CD4 cells

CD4 cells are a type of white blood cell that helps our bodies fight infection. They are the cells that HIV infects and uses to make copies. Your CD4 count is the number of CD4 cells in one cubic millimetre (written cells/mm<sup>3</sup> but in this guide we will just use the number eg 350) of blood. CD4 counts vary but an HIV negative adult would expect to have a CD4 count in the range of 400 to 1,600).

### Additional info

This guide 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 ART
- Guide to Changing Treatment
- HIV and your Quality of Life
- 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 explain in more detail words and phrases introduced in this one that might be unfamiliar or confusing, including CD4, viral load and resistance. We hope that you will use these booklets together when you need them. Your HIV clinic will probably have copies of any or all of them. You can also order them online: [www.i-base.info](http://www.i-base.info)

### Information service

i-Base provides a specialised HIV information service.

It is online at:

[www.i-base.info/qa/ask-a-question](http://www.i-base.info/qa/ask-a-question)

or by email at

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

Frequently asked questions about HIV and pregnancy are online at:

[www.i-base.info/qa/faqs-on-having-a-baby](http://www.i-base.info/qa/faqs-on-having-a-baby)

There is also a free telephone information support service at the following number: 0808 800 6013. The service is available from 12 to 4 pm on Monday, Tuesday and Wednesday

If you want to ask questions about HIV treatment and pregnancy, please contact us and we will try to help.

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

Good sources of community support:

- Positively UK, Women.

<http://positivelyuk.org/women/>

Body and Soul - a family HIV charity.

[www.bodyandsoulcharity.org/contact/](http://www.bodyandsoulcharity.org/contact/)



## Protecting and ensuring the mother's health

The most important things to consider for your baby to be healthy are:

- Your own health.
- Your own HIV treatment.

This cannot be stressed enough.

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

Preventing transmission and the health of your baby are directly linked to your treatment.

Prenatal counselling for HIV positive women should always include:

- Starting treatment if you are not already taking it when you get pregnant.
- ART and pregnancy if you are already taking it when you find out you are pregnant.
- Advice and discussion about how to prevent vertical transmission.

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. A healthy mother is vital for the health of a child.

## How HIV is transmitted to a baby

### How and why does vertical transmission happen?

Despite huge reductions in vertical transmission, we do not fully understand exactly how transmission happens. But, we do understand that there are many factors that affect the risk.

Of these, the mother's viral load is the most important. Vertical transmission can happen before, during or after birth. Other risks are having a low CD4 count or other infections.

Transmission is most likely to happen if the baby comes into contact with the mother's blood or other body fluids during pregnancy, delivery and breastfeeding.

Most transmissions happen during delivery.

Less often, transmission can happen during pregnancy before delivery. This is called in utero transmission.

This section has lots of medical words. We explain them on page 14.

## Medical words used during pregnancy

**Chorioamnionitis:** Inflammation of the membranes that surround the foetus (called the chorion and the amnion). Chorioamnionitis is usually caused by a bacterial infection.

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

**Foetal membranes:** The membranes surrounding the foetus.

**Foetoplacental circulation:** The blood supply in the foetus and placenta.

**Intrapartum:** Occurring during delivery (labour or child birth).

**In utero:** Within the uterus or womb before the start of labour.

**Maternal-foetal micro transfusions:** When small amounts of blood from the mother leak from the placenta to the baby during labour (or other disruption of the placenta).

**Mucosal lining:** 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.

**Placenta:** A temporary organ that develops in pregnancy joining 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. It is expelled from the mother's body after the baby is born and it is no longer needed. It is sometimes called the afterbirth. The placenta is a good barrier including to HIV. It prevents HIV from reaching the baby throughout most of pregnancy).

### Transmission during pregnancy (in utero)

We know that in utero transmission happens because some HIV positive babies, tested when they are a few days old, already have detectable virus in their blood. Usually it takes several weeks after infection until HIV shows in the blood. The rapid progression of HIV in some babies is also used as proof of in utero transmission.

In utero transmission might happen if the placenta is damaged and blood from the mother transfers into the blood circulation of the foetus.

Chorioamnionitis has been linked with damage to the placenta and increased HIV transmission risk.

This might be because HIV-infected cells travel across the placenta. Or it might happen because HIV slowly gets through different layers of the placenta, until the virus gets to the blood that reaches the foetus.

Having a high viral load and a low CD4 make in utero transmission more likely. In utero transmission might also be linked to when women start HIV drugs in pregnancy. It is more likely to happen if women start later in pregnancy and viral load stays higher for longer. Having tuberculosis (TB) at the same time as HIV is also a risk. And HIV also increases the risk of in utero transmission of TB.

### Transmission during labour and delivery (intrapartum transmission)

Scientists know that transmission occurs during delivery because:

- One in two babies who turn out to be infected test HIV negative in the first few days of life.
- Detecting HIV in babies increases rapidly during the first week of life.
- Some newborn babies have an immune response similar when an adult first becomes infected.

It is also shown by the success in preventing transmission:

- Treatment reduces transmission, even when only given in labour
- From Caesarean section, before labour starts.

Transmission during labour and delivery happens when a baby passes through the birth canal. This period has the highest risk of contact with the mother's blood and genital secretions.

HIV might also travel from the vagina or cervix to the foetal membranes and amniotic fluid, and through absorption in the digestive tract of the baby.

Or mixing of small amounts of mother and baby blood (maternal-foetal microtransfusion) might occur during contractions in labour.

The risk of transmission is increased in women not on ART if the baby takes a long time to be born after the membranes rupture (waters break

### Transmission from breastfeeding

HIV is present in breast milk - a bit like viral load in blood. The risk of infection comes because the virus in the milk most likely gets through the lining of the baby's stomach (and other GI tract).

The immature gut in a young baby is much easier with get through compared to an adult. It is unclear whether damage to the gut of the baby could increase the risk of infection. This might happen with early introduction of other foods, particularly solid foods, or water – but this research was done in women who were not on ART.

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 vertical transmission is not how it happens, but how we can stop it. We can do this by both using ART and not breastfeeding.

## Planning your pregnancy

Many HIV positive women become pregnant after they already know their HIV status. Many are already taking ART when they become pregnant.

In the UK in 2013, over 85% of HIV positive pregnant women were diagnosed before pregnancy. Over two thirds of these women became pregnant when they were already on ART.

Now ART is recommended for women at all CD4 counts, conceiving on treatment will be even more common.

If you already know that you are positive, you will probably have discussed the possibility of becoming pregnant as part of your HIV care. This is whether or not your current pregnancy was planned.

If you are planning to get pregnant, your doctor 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 currently over 98% of HIV positive pregnant women in the UK have uninfected babies.

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

## Timing of conception

Ovulation is part of a woman's menstrual cycle. It is when a mature egg is released from her ovary. The egg travels down the fallopian tube where it can be fertilised by a sperm.

Ovulation takes place about 14 days before the beginning of a woman's period.

A woman is most fertile the day before and the day of ovulation. This is because the egg survives about 24 hours.

Sperm can survive in a woman's body for several days. The whole fertile period is about 5 days before 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. This can be done by taking your temperature (which increases at the beginning of ovulation), or recording when you have your periods, 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 (PrEP)

PrEP is when a negative person takes antiretrovirals to protect them from HIV. PrEP is used occasionally to help make conception safer.

## How to become pregnant when one partner is HIV positive and the other is HIV negative

There is good news for couples in this situation.

Recent large studies, notably The HIV Prevention Trials Network (HPTN) Study 052 and the PARTNER study showed no transmissions from anyone on ART with undetectable viral load.

Successful ART is as effective as consistent condom use in limiting transmission and this is recommended for safe conception in the UK. Importantly, this is provided:

- Neither partner has another STI.
- The HIV positive partner has a viral load below 50 copies/mL for over 6 months.
- The HIV positive partner has regular viral load testing (3 to 4 monthly).

Doctors in the UK are recommended to discuss the impact of ART on transmission with all HIV positive people.

Timed intercourse, when the women is most fertile, is recommended for conception in couples that generally

prefer to use condoms as well as ART. Occasionally PrEP might be recommended for the negative partner.

*Note: This guide is mostly for HIV positive women but this advice could also be for HIV negative women with HIV positive partners.*

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

All couples can have difficulty with fertility. This might not be related to whether one or both partners are HIV positive.

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

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. This is important whether you are HIV positive or not.

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

There will 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 could encounter resistance to this help because you are HIV positive. You can and should complain if you do. You might want to choose a clinic that is more sympathetic and has experience with HIV positive parents.

## 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 sperm washing, 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 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

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 at first. But once I learned to live with it, I decided to start having a life again.

I 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 children!

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

We talked about how to do this and the possible options. We settled on the least complicated 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 viral load was undetectable.

My son is now five and half years old, HIV negative and very healthy. He is in year one at a school that he loves and he's doing very well. He has made lots of friends and loves to have a laugh. He's a cheeky little fella who orders me about but I love it. I am forever grateful and enjoy motherhood to the full.

Millie, Bristol

## HIV care and treatment during pregnancy

### What is antenatal care?

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

Antenatal care is not only about medicine and tests. It includes counselling and providing information like this guide. It also includes advice on your general health about taking exercise, eating well and stopping smoking.

It is important that your healthcare team has experience with HIV positive women. This includes your obstetrician, midwife, paediatrician and other support staff.

The people providing your care should understand the most recent developments in HIV treatment and preventing vertical transmission.

It is OK to ask anyone in your healthcare team whether or not they have looked after other HIV positive women in pregnancy.

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

Yes. Since 2015, everyone with HIV will be recommended to use ART, regardless of CD4 count. This includes pregnant women.

### What if I am already taking ART when I become pregnant?

Many women decide to have a baby when they are already on ART. UK guidelines recommend that women conceiving on effective ART should continue to take it.

## What HIV drugs will I take?

ART is usually a combination (or regimen) consisting of:

- Two HIV drugs from a family called NRTIs. This stand for nucleoside or nucleotide reverse-transcriptase inhibitor.
- A third drug from a different HIV drug class. This will be an NNRTI (a non-nucleoside reverse-transcriptase inhibitor), an integrase inhibitor, or a boosted protease inhibitor (PI).

The NRTIs are most likely to be tenofovir and FTC (emtricitabine). Or you might take abacavir with 3TC (lamivudine). In some cases you might take AZT (zidovudine) with 3TC.

The third drug is likely to be: an NNRTI (efavirenz or rilpivirine),

an integrase inhibitor (dolutegravir) or a PI (atazanavir or darunavir boosted with ritonavir or cobicistat).

There is still limited information about safety on some of the newer HIV drugs (eg dolutegravir, rilpivirine and cobicistat). If you are planning to become pregnant when you start ART, you should discuss this with your doctor before conceiving.

Some combinations have all your drugs in a single daily pill. This is called a fixed dose combination. Some have the two NRTIs in the same pill with the third drug taken separately (ie either two or three pills each day).

The i-Base guide, Introduction to Combination Therapy has more about each HIV drug:

<http://i-base.info/guides/starting>

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

Late diagnosis is defined as after 28 weeks of pregnancy but before labour starts. Being diagnosed this late is now rare in the UK. This is since HIV screening for all pregnant women was introduced.

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

Results from your viral load test will take less than a week, and sometimes only takes a few days. So some women in this situation will still be able to have a vaginal birth. This is if they start ART immediately and get an undetectable viral load by the time of delivery. Some combinations, particularly with integrase inhibitors get viral load to undetectable very quickly.

### **What about if my HIV status is only discovered when I am in labour?**

Even at this late stage there are things that can be done. In this situation a woman will be given a single dose of nevirapine immediately. ART of 3TC and AZT in a single pill and raltegravir should also be given straight away. Both nevirapine and raltegravir cross the placenta very rapidly.

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

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

### **Should I carry on taking ART after my baby is born?**

Yes. Now ART is recommended for everyone with HIV, it is routine to carry on taking ART after your baby is born. This is even if you had a high CD4 count before you started ART.

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

Approximately 8 out of 10 pregnant women taking ART will experience some sort of side effects. This is similar to the proportion of people taking ART 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.

The i-Base guide, *HIV and Your Quality of Life*, includes information on how to manage side effects.

<http://i-base.info/guides/side>

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

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

HIV drugs can sometimes 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 page 45.

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

You might feel more tired than usual. This is also to be expected, especially if you are starting ART and pregnant at the same time. Anaemia (low red blood cells) can cause tiredness. It is a very common side effect of both HIV and pregnancy. It is also common with AZT, which is why this drug is now rarely used. A simple blood test checks for this. If you have anaemia you might need to take iron supplements.

All pregnant women are at risk of developing a high blood sugar (hyperglycemia) and diabetes during pregnancy. Women taking PIs in pregnancy might 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, PIs have been associated with increased levels of bilirubin. While this is usually a measure of the health of your liver this is not always the case as with the PI atazanavir. Here bilirubin levels can be very high but without causing any problems.



## Screening and monitoring

### Will I need extra tests and monitoring?

Both pregnancy and HIV care require good monitoring.

HIV positive pregnant women do not need any extra monitoring for HIV. This should be the same as for any non-pregnant HIV positive adult.

You will have a resistance test before you start ART (unless you are diagnosed very late).

If you become pregnant before starting ART, you should have at least one CD4 count before you start. If you are already taking ART, this test will be when you first discover you are pregnant. You will have another CD4 test after the baby is born.

If you start ART in pregnancy you should have several viral load tests. The first test will be 2 to 4 weeks after starting. Then you will have at least one every trimester, at 36 weeks and delivery.

Liver tests are taken when you start ART and then at each antenatal visit.

Some doctors might recommend TDM (therapeutic drug monitoring) if your viral load is not declining at the expected rate. TDM is a blood test to check whether you are absorbing the right amount of a drug. Drug levels,

particularly of PIs, can vary between individuals. They can be lower during pregnancy. Occasionally this can lead to a dose adjustment.

Your doctor will also discuss your adherence and perhaps do another resistance test. Sometimes this might mean changing one or more of your HIV drugs.

You will be tested for hepatitis, syphilis and other STIs, anaemia and TB.

You might also be tested for other common infections that can be transmitted to your baby. The tests should be done as early as possible in your pregnancy. You should be treated for these if necessary.

Most tests you have will be routine for pregnant women. These might vary slightly from clinic to clinic. Routine tests include blood pressure, weight, blood and urine tests as well as foetal monitoring.

A test is called invasive if a needle or tube enters the body in some way. An example is amniocentesis which is a diagnostic test sometimes carried out during pregnancy. It can assess whether the foetus could develop, or has developed, an abnormality or serious health condition.

You might need an invasive test when your viral load is still detectable. In this case you should start ART with an integrase inhibitor such as raltegravir. You will also be given a single dose of nevirapine 2 to 4 hours before the test.

Unless you need extra care you will probably visit your clinic monthly (or even less if your viral load is less than 20 copies on ART from conception) for most of your pregnancy. Visits will be every two weeks after the eighth month.



## Prevention and treatment of other infections

### Opportunistic infection prevention and treatment

During pregnancy, treatment and prophylaxis for most opportunistic infections is similar to that for non-pregnant adults. Only a few drugs are not recommended.

The same drugs are recommended for pneumocystis jiroveci pneumonia (PCP), mycobacterium avium complex (MAC) and TB, if necessary.

Drugs for CMV, candida infections, and invasive fungal infections are not routinely recommended because of drug toxicity.

Pregnancy is not a reason to avoid treatment of very serious infections.

### Vaccines

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

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

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

### **Hepatitis A and B coinfections**

If you have active HBV you will need to take an ART regimen that includes tenofovir and either FTC or 3TC. These drugs act against HBV as well as HIV. You will also be vaccinated against hepatitis A (HAV) after the first trimester.

### **Hepatitis C coinfection**

You might discover you are coinfecting with both hepatitis C (HCV) and HIV through routine screening in pregnancy. Without HIV treatment there might be a 15% risk of transmitting HCV to the baby. ART will reduce this risk.

Women with HCV should not be treated with pegylated interferon or ribavirin. If you discover you are pregnant while being treated with these drugs, they should be stopped.

Your HCV will need to be carefully monitored.

You will be vaccinated against HBV and HAV.

If your HIV viral load is undetectable on ART you can have a vaginal delivery.

i-Base has a guide on Hepatitis C for People Living with HIV.

<http://i-base.info/guides/hepc>

## **TB coinfection**

It is important to treat TB in pregnancy. HIV/TB coinfection increases the risk of vertical transmission of both infections. TB can also increase the risk of the less common in utero transmission of HIV.

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

Most first-line TB drugs are safe to take in pregnancy.

The TB drug streptomycin is not recommended in pregnancy. It is now only rarely used in the treatment of TB in the UK.

## **Genital herpes**

Many people with HIV also have genital herpes. HIV positive women are more likely to experience a herpes outbreak during labour than negative women. Prophylaxis treatment for herpes with acyclovir is safe and is often recommended to reduce this risk.

Herpes is very easily transmitted from mother to child. Even with a viral load that is undetectable on ART, herpes sores contain high levels of HIV. The herpes virus can be released from the sores during labour. This will put the baby at risk from neonatal herpes.

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



## Delivering your baby

### Can I have a vaginal delivery?

BHIVA guidelines recommend vaginal delivery for mothers on ART with undetectable viral load <math>< 50</math> copies/mL. This is unless there are other complications.

You and your doctor will decide how you plan to deliver your baby (called mode of delivery) at 36 weeks. This decision will be made after reviewing your viral load results.

### Can I have a vaginal birth if I have had a caesarean before?

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

### Why is a caesarean sometimes recommended if you are HIV positive?

Before modern ART was available, planned caesarean section significantly reduced vertical transmission compared to vaginal birth. But there is no difference in more recent studies using ART and viral load testing.

Having a planned caesarean section does not offer any extra benefit if a mother's viral load is undetectable. But she might sometimes need one for another reason.

The choice is especially important if you might have more children in the future. This is because vaginal births with later pregnancies are more complicated.

If you need a planned caesarean section, it must be carried out before the start of labour and ruptured membranes. This is also called "pre-labour", "elective", or "scheduled" caesarean section.

## Caesarean section

Caesarean section involves surgery that cuts the abdominal wall to remove the infant from the uterus.

It is important to understand that if your HIV is well managed and your viral load is undetectable on ART, the risk to your baby is already close to zero. This is from either vaginal or caesarean delivery.

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

Some health teams are a bit more cautious with an HIV positive woman than an HIV negative woman with vaginal delivery.

### **When should I have a planned caesarean section?**

The main reason to consider a planned caesarean section is if your viral load is between 50 and 399 copies/mL at 36 weeks. Your doctor will discuss your most recent and previous viral load results, how long you have been on treatment and your adherence with you. If your viral load is above 400 copies/mL, a planned caesarean section is recommended. If the planned caesarean section is to prevent vertical transmission (and not because of other complications) you will need to have it at 38 to 39 weeks of pregnancy.

### **What if my waters break before my planned caesarean section?**

If your waters break before your caesarean section is planned then your viral load is important for deciding what to do. If your viral load is above 50 but less than 1000 copies/mL your medical team will consider an emergency caesarean section. If it is above 1000 copies/mL this will be strongly recommended.

### **Will a caesarean section now stop me having a vaginal birth in the future?**

If you have a caesarean section now, having a vaginal birth in the future is possible but more complicated.

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.



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

Many books on pregnancy recommend you pack a bag or small suitcase in advance. This is especially important if you plan a vaginal delivery. You might have to rush to hospital.

Include pyjamas or something to wear in hospital, a toothbrush and wash bag. Most important: include your HIV drugs. Remember to bring them with you even if you are not sure you are in labour.

Remember to take all your drugs on time as usual. This includes the day of vaginal delivery or planned caesarean. It is a critically important time to be sure that you don't miss any doses.

Remembering to do so might 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, and where you keep them. They can help you to remember to take your drugs on time.

## HIV drugs and the baby's health

In the past, some mothers and doctors were reluctant to take or prescribe HIV drugs during pregnancy. This was out of concern for unknown effects to the baby.

It is difficult to know if there are any long-term effects. All children born to HIV positive women in the UK (and many other countries) are monitored.

This safety monitoring covers all children born to HIV positive women in the UK (and many other countries). This close care will provide important safety information in the future.

The biggest risk to a baby born to a mother who is HIV positive is the risk from HIV itself. This can be prevented with ART.

### Will HIV drugs affect the baby?

So far, all the available evidence, over more than 25 years, shows that HIV drugs appear to be safe.

This even includes with a few reports that 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 ART. This is particularly with PIs.

A British study found an overall prematurity rate of 13 out of 100 babies. This is slightly higher than the rate in HIV negative women in the UK of about 6 to 8 out of 100.

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

### **Can HIV drugs cause birth defects?**

To date there is no evidence that currently used ART increases the risk of birth defects.

### **What about anaemia?**

Anaemia has been seen in babies born to mothers taking HIV drugs. This passes quickly and rarely needs a transfusion.

### **What about bilirubin?**

If you are taking atazanavir, the levels of bilirubin in the baby might be higher than normal. Your healthcare team will follow your baby's bilirubin levels very carefully. The baby might have phototherapy treatment with light using a special machine to reduce the levels of bilirubin.

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

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

Yes. All babies born to HIV positive mothers on ART will be monitored very carefully.

## After the baby is born

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

Adherence! This means finding a way to make sure you continue to take your HIV drugs. This still needs to be exactly as prescribed, and follow the same advice to take them with food, if you do.

Your adherence to ART after the baby is born is critical.

Many women have excellent adherence during pregnancy. But with a change in routine, it is easy to forget your own health.

This is hardly surprising. Having a new baby can be a huge shock.

It can be unsettling in both good and bad ways. Your sleep patterns might change completely and you are unlikely to get enough sleep. When you do sleep, you might easily miss a dose. Keeping a record, even though you are now doing so many other things, might be a good idea.

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

In serious cases, some women can have postnatal depression. This needs special support. It is important to talk about your feelings after your baby is born.

Many mothers find the best way to remember to take their own ART is to change it to match the times that their new baby takes HIV drugs. So if your baby has two doses a day and you have two doses, you can both take these at the same time.

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

The usual HIV antibody test is not used to test for HIV in babies. Babies born to HIV positive mothers will always test HIV positive using an HIV antibody test.

This is normal and does not mean your baby has HIV. Your baby shares your immune responses that the antibody test looks for. It sometimes takes up to 18 months for these responses to gradually disappear.

The baby will be tested using an HIV PCR DNA or RNA test. These tests look for virus in the baby's blood.

In the UK, it is good practice to test the baby on the day she or he is born. The test is repeated after six weeks and again at three months.

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

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

## To check the baby is HIV negative

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

HIV PCR RNA this is similar to the HIV DNA test and is the same test used to measure viral load.

The tests amplify or multiply HIV DNA or RNA in the test tube so that it can be more easily detected.

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

Yes. All baby's need to take a short course of HIV drugs for the first four weeks of life, if their mother is HIV positive.

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

Plan a routine where you and your baby take these meds together at the same time.

### **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 going back to or starting oral contraception (the pill) will not be recommended if you started ART in pregnancy.

This is because some HIV drugs can reduce the levels of some oral contraceptives. This means they will not be foolproof birth control.

Please make sure both your home doctor (GP) and your HIV doctor knows about this and can advise you.



## Feeding your baby

HIV can be transmitted to the baby from breast milk.

This is why HIV positive mothers in the UK are routinely advised to use bottles and infant formula milk (this advice is different in other parts of the world, particularly where there is not access to clean water).

### Bottle-feeding and free formula milk

All HIV positive mothers in the UK are strongly recommended not to breastfeed. This is regardless of their CD4, viral load or ART.

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 very low in the UK. Using formula feeding has contributed to these very low rates. It is as important as using ART, the choice of delivery and all the other care.

All HIV positive mothers in the UK should be supported to formula feed their babies. 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.

### 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.

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.

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

There are many other reasons why HIV negative women do not breastfeed.

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 Organization (WHO) infant feeding guidelines are for women in countries where replacement feeding is not safe or available. WHO recommends that breastfeeding is safer if the mother or the baby receives HIV drugs.

BHIVA and the Children's HIV Association (CHIVA) recommend the complete avoidance of breastfeeding for HIV positive mothers. This is whether the mother is healthy, has an undetectable viral load or on ART.

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 ART:

- How many pills?
- 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?
- Use a weekly pill box. Then you can see if you miss a dose. If your clinic does not provide one, most chemists sell them for about £2. i-Base can sometimes provide these free – call the phoneline for details.
- Take extra HIV 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.
- Ask friends to help you remember difficult dose times like when you go out at night.
- Use the alarm on your mobile phone or watch or computer for all doses. Then take your drugs when it beeps! Perhaps set the alarm just after the right time, so it is a reminder and not something you rely on.
- Link your HIV drugs to another daily routine, such as brushing your teeth.
- 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 ART what they do. How well are they managing?
- Most HIV clinics can arrange for you to talk to someone who is already taking the same ART if you think that would help.
- Make sure that you contact your hospital or clinic if you have serious difficulties with side effects. Staff there can help and discuss switching treatment if necessary.

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

- Eat smaller meals and snacks more frequently instead of eating a few larger meals.
- Try to eat more bland food.
- Avoid spicy, greasy or strong-smelling food.
- Try eating cold rather than hot food. Or let hot food cool before you eat it.
- Do not eat in a room that is stuffy or that has lingering cooking smells.
- 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.
- Eat at a table, rather than lying down. Do not 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.
- Leave some dry crackers by your bed. Eat one or two before you get up in the morning.
- Peppermint might be helpful. It can be taken in tea or in chewing gum.
- Ginger might be helpful. It can be used in capsule or as ginger root powder. Fresh root ginger peeled and steeped in hot water might help.





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## 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:

FREEPOST RSJY-BALK-HGYT, i-Base, 57 Great Suffolk Street, London SE1 0BB.

Or made directly online at: <http://www.surveymonkey.com/s/BSKSVYR>

1. How easy was the information in this guide to understand?

Too easy     Easy     Difficult     Too difficult

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None     A little     Most     All

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Please include a contact email address if you would like us to reply.

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