i-base
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Guide to HIV, pregnancy & women's health

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Watch for out-of-date information

Diagnosed with HIV in pregnancy
How HIV is transmitted to a baby
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Having an HIV negative baby

Contents

This booklet is about HIV and pregnancy.

It explains what to do if you are diagnosed with HIV in pregnancy. It also explains what to do if you already know you are HIV positive and decide to have a baby.

The booklet includes information about mothers' health, using antiretrovirals during pregnancy and the babies' health.

It includes information on how to have an HIV negative baby if you are HIV positive.

It also includes information about safe conception for couples where one partner is positive and one is negative.

The guide was written and compiled by Polly Clayden for HIV i-Base. Thanks to the advisory board of HIV positive people, activists and health care professionals for comments and the people who shared their stories. Particular thanks to Angelina Namibia and Memory Sachikonye.

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

Introduction

This is the 6th edition of the i-Base pregnancy guide.

Since our last edition, the British HIV Association (BHIVA) guidelines have been updated and research findings have been reported. These include:

- An updated section on safe conception for couples where one partner is HIV negative and one is HIV positive. This has more emphasis on safe conception using antiretroviral therapy. It also discusses the reduced risk of HIV transmission between partners. So although most of the information included in the booklet is for HIV positive women, this section is also relevant to HIV negative women with HIV positive men.
- A stronger emphasis on starting treatment early enough in pregnancy to ensure your viral load is undetectable at delivery.
- More detailed information on using antiretrovirals in different pregnancy scenarios including coinfection with hepatitis B and C.
- The recommendation that mothers on antiretroviral therapy with an undetectable viral load and no other complications deliver vaginally.
- Continuing antiretroviral therapy after delivery for women not indicated for treatment for their own HIV is addressed for the first time.
- A continued strong recommendation on the importance of complete avoidance of breast feeding despite new research relevant to countries where this is not possible.

The excellent news is, with good management focusing on a woman's health and choice, there is little risk of transmission to her child for an HIV positive mother delivering in the UK today.

Our most recent reports show a 1 in 1,000 transmission rate for women receiving combination antiretroviral therapy (ART) 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 transmission rate reported and represents a significant advance in the information available to women planning a family or already pregnant.

We explain what all these terms and options mean and when they are appropriate.

Excellent news too is that people with HIV are living longer and healthier lives so an HIV positive mother in the UK today can also expect to be around to watch her child grow up!

British HIV Association (BHIVA) and Children's HIV Association (CHIVA) Guidelines for the Management of HIV Infection in Pregnant Women 2012 are online at:

http://www.bhiva.org/documents/Guidelines/Pregnancy/2012/hiv1030_6.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:

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

Background and general questions

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

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

If you have just been diagnosed with HIV

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

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

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

There are lots of people, services and other source of information to help you. The advice that you receive from these sources and others may be different to that given to pregnant women generally. This includes information on medication, Caesarean section (C-section) and breastfeeding.

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

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

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

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

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

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

Jo, London

Can HIV positive women become mothers?

Yes, and HIV treatment makes this much safer.

Women around the world have safely used antiretroviral drugs in pregnancy now for almost 20 years. Currently this usually involves taking at least three antiretroviral drugs, which is called combination therapy, ART or HAART.

Antiretrovirals have completely changed the lives of people with HIV in every country where they are used.

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

Your HIV treatment will protect your baby

The benefits of treatment are not just to your own health. Treating your own HIV will reduce the risk of your baby becoming HIV positive to almost zero.

Without treatment, about 25 percent of babies born to HIV positive women will be born HIV positive. One in four is not good odds, though, especially because modern HIV treatment can almost completely prevent transmission.

How is HIV transmitted to a baby?

The exact way that transmission (when the virus passes from one person to another) from mother to baby happens is still unknown. Mother to baby transmission is known as vertical transmission. The majority of vertical transmissions happen near the time of, or during, labour and delivery (when the baby is being born). Vertical transmission can also occur through breastfeeding.

Certain risk factors seem to make transmission much more likely. The biggest of these is the mother's viral load, which means the amount of virus in your blood.

As with treatment for anyone with HIV, one important goal is to reach an undetectable viral load. Viral load tests measure the amount of virus in your blood. The measurements are in copies per millilitre (copies/mL). Undetectable viral load is currently considered to be below 50 copies/mL. When we talk about an undetectable viral load in this guide, that is what we mean. If a mother's viral load is undetectable when her baby is born, the risk of vertical transmission is almost zero.

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

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

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

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

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

Angelina, London

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, if she tests positive, she can be aware of how she can protect her baby from HIV.

Is it really safe to take HIV medicines during pregnancy?

Reducing the risk of a baby becoming HIV positive was an early benefit of antiretrovirals. Although, pregnant women are often advised against taking medications, this is not the case with HIV treatment. This difference can sometimes seem confusing.

No one can tell you that it is completely safe to use antiretrovirals while you are pregnant but thousands of women have taken these medicines all over the world without any complications to their baby. This has resulted in many healthy HIV negative babies.

During your prenatal discussions, you and your doctor will discuss the benefits and risks of treatment options for you and your baby.

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

http://www.apregistry.com

So far, the registry has not seen an increase in the type or rate of birth defects, in babies whose mothers have been treated with currently used antiretrovirals, compared to the babies born to mums not using 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. Combination therapy has fulfilled my dreams of becoming a mother again.

Jenny, London

Will being pregnant make my HIV worse?

Pregnancy does not make a woman's HIV get any worse.

However, being pregnant may cause a drop in your CD4 count. CD4 cells are a type of white blood cell that helps our bodies fight infection. They are the cells that HIV infects and uses to make copies of itself. Your CD4 count is the number of CD4 cells in one cubic millimetre (written cells/mm3 but in this guide we will just use the number eg 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. Nearly all HIV treatment guidelines recommend starting treatment at 350 (and earlier in some cases).

The CD4 drop in pregnancy 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 if your CD4 falls below 200. Below this level, you are at a higher risk from opportunistic infections. These are infections that occur after HIV has damaged your immune system.

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

Also sometimes if you start taking ART 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 ART.

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

Additional info

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

- Introduction to Combination Therapy
- Guide to Changing Treatment
- 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 may be unfamiliar or confusing, including CD4, viral load and resistance.

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

http://www.i-base.info

Information service

i-Base provides a specialised HIV information service.

It is online at:

http://i-base.info/qa/ask-a-question?first=yes

or by email at questions@i-base.org.uk

Frequently asked questions about HIV and pregnancy are online at:

http://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:

From Pregnancy to Baby and Beyond peer support project at Positively UK. Women (and men) can either self refer or be referred by their clinic.

http://www.positivelyuk.org/pregnancy_and_beyond.php

anamiba@positivelyuk.org or 02077130444

Body and Soul - a family HIV charity.

http://bodyandsoulcharity.org/contact/

Protecting and ensuring the mother's health

Your own health and your own treatment are the most important things to consider for ensuring 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.

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. Your health and care are very important.

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

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

Prenatal counselling for HIV positive woman should always include:

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

Your child is certainly going to want you to be well and healthy as he or she grows up. And you will want to be able to watch him or her go to school and become an adult. A healthy mother is vital for the health of a child.

Principles of care

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

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

How HIV is transmitted to a baby

How and why does transmission happen?

Despite remarkable achievements in reducing vertical transmission, we do not fully understand how it happens. What we do understand, though, is that there are many factors that affect transmission.

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

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

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

This section has lots of medical words. We have explained them on page 16.

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 by infected cells travelling across the placenta, or by progressive infection of different layers of the placenta until the virus reaches the foetoplacental circulation.

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

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

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

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

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

Placenta is a temporary organ that develops in pregnancy and joins the mother and 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 (GI) tract is the tube that runs from the mouth to the anus and where we digest our food. The gastrointestinal tract begins with the mouth and then becomes the oesophagus (food pipe), stomach, duodenum, small intestine, large intestine (colon), rectum and, finally, the anus.

During labour and delivery (intrapartum transmission)

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

This could happen through ascending infection from the vagina or cervix to the foetal membranes and amniotic fluid, and through absorption in the digestive tract of the baby.

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

Scientists know that transmission occurs during delivery because:

- 50 percent of babies who turn out to be infected test HIV negative in the first few days of life.
- There is a rapid increase in the rate of detection of HIV in babies during the first week of life.
- The way that the virus and the immune system behave in some newborn babies is similar to that of adults when they first become infected.

It is also shown by the success in preventing it happening. This includes:

- Treatments that have reduced transmission risk, even when given only in labour
- Delivery of the baby by Caesarean section, before labour starts.

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

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

Breastfeeding

HIV in breast milk most likely gets through the mucosal lining of the gastrointestinal tract of infants.

The gastrointestinal tract of a young baby is immature and more easily penetrated than that of an adult. It is unclear whether damage to the intestinal tract of the baby, caused by the early introduction of other foods, particularly solid foods, could increase the risk of infection.

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

The most important thing to know about vertical transmission is not how it happens, but how we can prevent it from happening. We can do this with antiretrovirals.

Planning your pregnancy

Many HIV positive women become pregnant when they already know their HIV status. Many women are also already taking ART when they become pregnant. If you already know that you are HIV positive, you may have discussed the possibility of becoming pregnant as part of your routine HIV care—whether this pregnancy was planned or not.

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

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

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

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

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

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

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

Recently there has been good news for couples in this situation.

In January 2013, BHIVA and the Expert Advisory Group on AIDS (EAGA) issued a position statement on the use of ART by HIV positive people to reduce HIV transmission.

The statement refers to a very large study that in 2011 reported some very important news. The results from the HIV Prevention Trials Network (HPTN) Study 052 provided proof that ART can make HIV positive people less infectious to their HIV negative partners.

The study was conducted in several countries with over 1700 couples where one partner was HIV positive and the other HIV negative. It compared the effect of starting ART immediately (CD4 count between 350 and 550) to delaying starting until the positive partner reached a CD4 count of less than 250.

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

The BHIVA/EAGA statement notes that successful ART use by the HIV

positive person is as effective as consistent condom use in limiting transmission.

Importantly, it stresses that this is provided the following conditions are met:

- 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 (3-4 monthly).

Health care professionals in the UK are recommended to discuss the impact of ART on transmission with HIV positive people and the possibility of starting ART for this purpose.

You can find the position statement on the Department of Health website at:

https://www.wp.dh.gov.uk/publications/files/2013/01/BHIVA-EAGA-Position-statement-on-the-use-of-antiretroviral-therapy-to-reduce-HIV-transmission-final.pdf

Also in January 2013 a systematic review (when all the published research on a topic is looked at all together in order to answer a question) was presented of publications reporting rates of HIV transmission in heterosexual couples, when the positive partner had an undetectable viral load. This review included results from HPTN 052 an also found a minimum risk of transmission.

For many people these developments are very reassuring, particularly those who meet the ART and viral load conditions and choose to have sex without condoms.

Couples who generally use condoms will be advised that the recommended way of conception is by timed intercourse when the woman is most fertile. Sometimes the negative partner will be recommended to take PrEP.

Occasionally some couples might still be anxious about transmission with unprotected intercourse even though they meet the ART, adherence and viral load conditions. Or they might not meet the conditions. In these cases they might be recommended and consider other methods.

Timing of conception attempt

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

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

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

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

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

This is when an HIV negative person takes antiretrovirals to prevent them from getting HIV. This method is sometimes recommended to help make a conception safer.

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

When the man is HIV positive with a negative partner, it is possible to use a process called sperm washing. This involves the man giving a semen sample to a clinic.

A special machine then spins this sample to separate the sperm cells from the seminal fluid. (Only the seminal fluid contains HIV; sperm cells themselves do not carry HIV).

The washed sperm is then tested for HIV.

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

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

Very few clinics offer this service in the UK but the clinic with the most experience is the Chelsea and Westminster Hospital in London. The Chelsea and Westminster assisted conception unit can be contacted on 0208 746 8585. It is not always possible to obtain this procedure on the NHS.

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

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

Of note the National Institute of Clinical Excellence (NICE) 2013 draft fertility guidelines include a section on viral transmission with the question: "What is the effectiveness and safety of sperm washing to reduce the risk of viral transmission?" It specifically looks at transmission risk of HIV when HIV positive male partners are on treatment.

It concludes that generally recommendations should be ART-protected intercourse. Where these conditions are not met couples would still be advised to have sperm washing. It acknowledges that there might be some couples who would still request sperm washing, despite the HIV positive man being adherent on ART with a viral load of less than 50 copies/mL. For this they recommend that the request should be considered.

In situations where ART is being used and viral load is undetectable the guidance explains that sperm washing only reduces viral load

rather than eliminating it, so there would be little or no added benefit from this option.

The guidance is here:

http://www.nice.org.uk/nicemedia/live/14078/62770/62770.pdf

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

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

This is a very safe way to protect the man from HIV.

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

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

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

When both partners are HIV positive

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

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

All these options involve very personal decisions. Knowing and judging the level of risk is also very individual. All methods of becoming pregnant carry varying degrees of risk, and chance of success (and sperm washing and fertility treatment may involve a cost if you are unable to access them on the NHS).

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

Can I get help if I am having difficulty conceiving?

All couples could experience some fertility difficulties, regardless of who is HIV positive or if both are.

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

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

Is fertility treatment available to HIV positive people?

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

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

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

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

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

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 in the beginning. But once I learned to live with it, I decided to start living my life again.

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

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

We talked about how to achieve this and the possible options. We settled on the least complicated option – unprotected sex during my ovulation period. In a couple of months, I conceived!

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

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

My partner remains HIV negative.

Millie, Bristol

HIV care and treatment during pregnancy

What is prenatal care?

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

Prenatal care is not only about medicine and about tests. It includes counselling and providing information like this guide. It also includes advice on your general health such as taking exercise and stopping smoking.

As with all aspects of HIV care, it is very important that members of your healthcare team have had specialist experience with HIV positive women. This includes your obstetrician, midwife, paediatrician and other support staff.

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

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

Everyone with a CD4 count of 350 or less needs to start ART. As do some people with higher CD4 counts but HIV-related health reasons (like an opportunistic infection or hepatitis coinfection).

Some HIV positive women with CD4 counts above 350 might have started ART to protect their negative partners.

So some women will already be on ART when they become pregnant.

Some women with higher CD4 counts will receive a short course of ART during pregnancy, to prevent vertical transmission.

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

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

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

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

BHIVA guidelines recommend that women conceiving on an effective ART regimen should continue this.

What if I need treatment for my own HIV?

All HIV positive people with CD4 counts of 350 and below should be on ART, including pregnant women. Women needing ART for their own health should start ART as soon as possible.

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

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

There are two main reasons for delaying treatment.

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

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

Symptoms of morning sickness are very similar to the nausea that can occur when starting ART. This can also make adherence harder. If you have morning sickness you might delay starting treatment until after the first trimester.

All women should have started ART by 24 weeks of pregnancy. This will mean you have the have time to get your viral load to undetectable. That way you have the least risk of transmission and you will be able to have a vaginal birth.

If you are diagnosed at 28 weeks or after you will need to start ART straight away.

If your CD4 count is very low and your viral load high and/or you have an opportunistic infection, or you are diagnosed late in pregnancy, ART should not be delayed.

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

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

i-Base has a guide, Introduction to Combination Therapy that you could use to find out more about antiretrovirals:

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

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

A European study (including data from the UK) looked at use of non-AZT ART in pregnant women between 2009 and 2009. About 60 percent of women received this in the study. There were no greater rates of vertical transmission, undetectable viral load at delivery or abnormalities in the babies for women who received non-AZT ART.

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

Nevirapine has been used widely in pregnancy but there is a caution against starting nevirapine-based ART for women with CD4 counts above 250. This is because of a risk of liver (hepatic) toxicity. It is only recommended for women with lower CD4 counts.

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

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

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

ART is not generally recommended at much higher than 350 CD4 unless you have HIV-related health problems or want to use treatment to protect your negative partner.

If you do not need treatment for you own health you will still need to take antiretrovirals to prevent transmission to the baby. You will also need to start by 24 weeks of pregnancy or as soon as possible after that.

The recommended NRTI backbones are the same as for women who need treatment for their own HIV.

The third drug will probably be a boosted PI. A PI has an advantage over an NNRTI if you plan to stop ART straight after your baby is born. Your body processes PIs relatively quickly. You can stop all the drugs in your ART combination with a low risk of resistance.

For women with a viral load of less than 100, 000 copies/mL before treatment a third NRTI, abacavir, is sometimes recommended, instead of a PI.

Occasionally, a woman with a very low viral load (less than 10,000 copies/mL), not on treatment, might choose to use a short course of AZT alone (monotherapy) with a planned Caesarean section. This strategy is being used less and less in the UK. Only about 2 percent of HIV positive women chose this way of preventing transmission to their baby in 2009 to 2010.

A very small proportion of HIV positive people, known as elite controllers, have undetectable viral loads less than 50 copies/mL for years without treatment. This is very rare, only about 1-in-300 HIV positive people are elite controllers. Pregnant elite controllers could either use AZT monotherapy or a 3-drug ART regimen including abacavir, 3TC and AZT.

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

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

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

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

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

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

What 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.

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

Both nevirapine and raltegravir cross the placenta very rapidly.

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

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

Can I carry on taking ART after a short course to prevent vertical transmission?

If you had a CD4 count between 350 and 500 before you started and you have no other reason to continue treatment you could decide to either stop or continue your ART. If you are doing well, not experiencing unmanageable side effects and are adherent, continuing might be a good choice. If you haven't found taking ART very easy in pregnancy and are not sure if you can be adherent at the moment then it might be better to stop.

You can discuss the advantages and disadvantages with your healthcare team.

If your CD4 was above 500 before you started you will usually stop ART, unless you wish to continue to take it protect your partner or there is a health related reason to carry on.

Are any antiretrovirals not recommended in pregnancy?

The liquid formulation of amprenavir, a less commonly used PI, 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.

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

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

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

Nevirapine is not recommended for women with higher CD4 counts (above 250).

Should I expect more side effects when I am pregnant?

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

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

i-Base have produced a guide HIV and Your Quality of Life, which includes managing side effects.

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

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

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

Many antiretrovirals can cause nausea and vomiting.

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

Tips to reduce nausea, and help with adherence are included on page 46.

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

You may feel more tired than usual.

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

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

Women taking PIs 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, 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.

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 the UK. Consequently the risk of lactic acidosis is now extremely low.

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, as far as HIV is concerned, compared to non-pregnant HIV positive women.

You will have a resistance test before you start ART (unless you are diagnosed very late). If you take a short course and stop another one is recommended then.

If you conceive on ART or do not need ART for your own health, you should have a minimum of one CD4 count before you start (or when you first discover you are pregnant if you are already on ART) and one at delivery.

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

Liver function tests should be done when you start ART and then at each antenatal visit.

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

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

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

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.

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

pressure, weight, blood and urine tests as well as foetal monitoring.

An invasive test is a procedure or examination that needs the body to be entered in some way, either through a needle or with a tube. If a test is invasive and cannot be delayed until your viral load is undetectable, you will be recommended to start ART with raltegravir in the combination. You will also be given a single dose of nevirapine 2 to 4 hours before the procedure.

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.

Prevention and treatment of other infections

Opportunistic infection prevention and treatment during pregnancy

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

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

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

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

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

Vaccine use while pregnant

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

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

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

Hepatitis B coinfection

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

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

If your CD4 was less than 500 when you started ART you should continue taking it after delivery. If it is above 500 you might also consider

continuing. If you do decide to stop you will need to have your liver function carefully monitored.

If your liver is already damaged – even if you are above 500 you should continue ART.

Hepatitis C coinfection

If you are coinfected with hepatitis C virus (HCV) and HIV—you may discover this through routine screening in pregnancy—there is a risk of transmission of HCV of up to 15 percent. Treating your HIV will reduce this risk of transmitting HCV. You will need to take ART regardless of your CD4 count.

Mothers with HCV should not be treated with pegalated interferon or ribarvirin. If you discover you are pregnant while being treated with these drugs, they should be stopped.

Your HCV will need to be carefully monitored.

You will be vaccinated against HBV and HAV.

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

If your CD4 was 350 to 500 before you started ART should continue to take it after your baby is born regardless of your liver damage through HCV.

You should continue too if your CD4 is less than 500 and your liver is damaged. If your HCV has not progressed yet and your CD4 is greater than 500 you could stop ART unless you need it for another reason. But if your liver is damaged continuing ART is preferable.

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. Additionally HIV/TB coinfection increases the risk of vertical transmission of both infections. TB can also increase the risk of the less common in utero (in the womb rather than during labour) vertical transmission of HIV.

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

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

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

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

Treating recurrent genital herpes during pregnancy

Many women with HIV also have genital herpes. HIV positive mothers

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

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

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

Delivering your baby

Can I have a vaginal delivery?

BHIVA guidelines recommend that mothers on ART with an undetectable viral load at 36 weeks of pregnancy, and no other complications, deliver vaginally.

Elite controllers can also deliver vaginally.

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

Can I have a vaginal birth if I have had a 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, 70 percent of those in this situation manage a vaginal delivery.

Caesarean section

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

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

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

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

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

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

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

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

When should I have a planned Caesarean section?

If your viral load is between 50 and 399 copies/mL at 36 weeks you should consider a planned Caesarean section. Your doctor will discuss your most recent and previous viral load results, how long you have been on treatment and your adherence with you. Your own preference is important in this decision.

If your viral load is above 400 copies/mL, a planned Caesarean section is recommended.

If you do not need treatment for your own health and choose to use AZT alone, a planned Caesarean section will be necessary to reduce transmission risk to minimal levels.

If the planned Caesarean section is to prevent vertical transmission (and not for another reason) you will need to have at 38 to 39 weeks of pregnancy.

What if my waters break before my planned Caesarean section?

If your waters break before your planned Caesarean section is due and your viral load is 50 to 999 copies/mL your medical team will consider an emergency Caesarean section. If it is above 1000 copies/mL you will be strongly recommended to have one.

Will a Caesarean section now stop me having a vaginal in the future?

If you have a Caesarean section now, having a vaginal birth in the future is 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 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 antiretrovirals. Remember to bring them with you even if you are not sure that you are in labour.

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

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

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

HIV drugs and the baby's health

In the past particularly, some mothers and doctors have been reluctant to use or to prescribe antiretrovirals during pregnancy. This is out of concern for unknown effects to the baby.

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

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. Antiretrovirals can prevent this.

Will antiretrovirals affect the baby?

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

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

Prematurity

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

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

This should not be a reason for a mother to avoid treatment in pregnancy, particularly if she needs it for her own health. It is important to be aware of the risks and options 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 antiretrovirals cause birth defects?

There have been very few reports of birth defects in babies whose mothers have taken these drugs in pregnancy. The only caution at the moment is possibly with the two drugs ddI and nelfinavir, neither of which is recommended in the UK.

What about anaemia?

Anaemia has been seen in babies born to mothers on antiretrovirals but this passes quickly and rarely requires a transfusion.

What about bilirubin?

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

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

Will my baby be monitored for these symptoms?

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

After the baby is born

What will I need to consider for my own health?

Adherence! This means taking your drugs exactly as prescribed.

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

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

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

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

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

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

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

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

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

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

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

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

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.

Will my baby need to take antiretrovirals after he or she is born?

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

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

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

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

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

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

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

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

Feeding your baby

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

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

Bottle-feeding and free formula milk

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

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

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

All HIV positive mothers in the UK

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

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

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

Can I breastfeed occasionally?

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

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

Sometimes people ask me why I do not breastfeed

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

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

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

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

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

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

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

Mem, London

Breastfeeding

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

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

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

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

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

Further reading:

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

Tips to help adherence

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

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

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

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

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

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

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

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

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

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

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

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

Tips to help with morning sickness or drug-associated nausea

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

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 07	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 2002 etc).

Drug name and dose	Date started (month / year)	Date stopped (month/year)	Reason
e.g efavirenz 600 mg	Feb 03	Jan 04	Not sleeping

Other notes

Other notes

Other notes

Other notes

Further information

If you have questions after reading this guide or would like to talk to someone about treatment contact the i-Base information service by phone or email.

0808 800 6013

questions@i-Base.org.uk

Full prescribing information on individual HIV drugs and other scientific documents are available in most European languages from the European Medicines Agency (EMA):

www.ema.europa.eu

The following community sites include information on new drugs, and include updated reports from HIV conferences.

www.i-Base.info

www.aidsinfonet.org

www.aidsmeds.com

www.natap.org

www.aidsmap.com

www.tpan.com


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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

2. How much of the information did you already know?

☐ None ☐ A little ☐ Most ☐ All

3. Did the information help you feel more confident when speaking to your doctor?

☐ Yes, a lot ☐ Yes, a little ☐ Maybe ☐ No

4. Which information did you find most useful?

5. Do you still have questions after reading this guide?

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Call us on
0808 800 6013

i-Base Treatment Information Phoneline

Monday to Wednesday
12 noon to 4pm

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

questions@i-Base.org.uk
www.i-Base.info/questions