

PREGNANCY AND HIV DISEASE



issues that positive women
may face when they're pregnant

A PUBLICATION FROM

PROJECT

inform

Information,
Inspiration and
Advocacy for People
Living with HIV/AIDS

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Motherhood is a choice, and this publication is intended for HIV-positive women who are pregnant and want to learn more about managing pregnancy and HIV. This publication will provide you with: basic information about HIV and pregnancy; what steps you need to take to ensure a healthy pregnancy and

delivery; and how to get the most out of your own HIV treatment and care and the steps to take once you have had the baby. This publication will *not* discuss: options on how to conceive if you're interested in becoming pregnant or issues to consider when deciding whether to continue or end a pregnancy.

if you're thinking about pregnancy ...

If you are considering getting pregnant, there are many issues to consider in addition to HIV, such as your age, other medical conditions like diabetes or high blood pressure, whether you smoke, among others. Talking with a medical provider you trust can help you decide when it would be a good time to start trying to get pregnant. For example, some women start taking vitamins, stop smoking or switch their anti-HIV regimens before trying to get pregnant. Also, you could discuss with your provider what is known about the safest way you and your partner can conceive.



You just found out that you're both HIV-positive and pregnant ...

If you've just been diagnosed with HIV and found out you're pregnant at the same time, you are probably feeling strong emotions that may include anxiety, concern or fear. Depending on whether your pregnancy is planned or wanted, difficult emotions can overshadow other feelings of joy or excitement for a time. This is natural and you should give yourself time to deal with your emotions.

Talking with a counselor about your feelings and with a doctor about your pregnancy, HIV diagnosis, and options for care and treatment will help you plan your next steps and make decisions about how you want to proceed with your pregnancy. You may also find resources in your community like support groups, women's organiza-

tions and AIDS service organizations. Take time to come to terms with your diagnosis as best you can and then make a decision about how you want to proceed with your pregnancy.

You've been HIV-positive for awhile and just found out that you're pregnant ...

This is a good time to talk with your doctor about your overall health and your HIV disease. If you're not already on anti-HIV medications, your doctor may suggest you start them depending on factors such as how many months you're along in your pregnancy, your viral load and CD4+ cell count. You should start prenatal care, preferably with an OB/GYN who has some experience with HIV and pregnancy.

The best decisions are the ones that are yours and that are informed. Use the information here to help guide your decisions. Call Project Inform's toll-free Infoline at 1-800-822-7422 if you have other questions.

frequently asked questions about HIV and pregnancy ...

Can I become a mother if I'm HIV-positive?

YES! Especially with the development and advances in HIV research and treatment, more HIV-positive women are choosing to conceive or continue with their pregnancies. HIV treatment can benefit your own health and also greatly reduce the risk of passing HIV to your infant.



Will pregnancy make my HIV disease worse?

NO. Pregnancy does not affect the course of HIV disease. It will not make your HIV worse or better. During pregnancy, there's a normal drop in CD4+ cell counts that usually rebounds after birth to pre-pregnancy levels. This is normal for any woman, regardless of HIV status. However, if your CD4+ cell count falls below 200, you are at a higher risk for OIs.

Can I take anti-HIV medicines while I'm pregnant?

Pregnant women who are HIV-positive will follow the same general guidelines for taking anti-HIV therapy as "non-pregnant" adults. Depending on a woman's HIV disease status (her viral load and CD4+ cell count), a doctor may or may not recommend starting or continuing anti-HIV therapy (typically at least three drugs). However, certain anti-HIV drugs can harm the developing baby, so they are not recommended for use during pregnancy. See *Medications and Procedures to Consider* on pages 8 & 9.

AZT (zidovudine, Zerit) has been studied widely in pregnant women and is the only FDA-approved drug to use in reducing the risk of transmission from mother to child. ACTG 076 was the famous study which showed that AZT could protect a baby from getting HIV. During the study, mothers took AZT before and during labor and the babies were given the liquid form of AZT daily for six weeks after birth. The risk of transmission was reduced from 25% to 8%. With the development and use of anti-HIV therapy, transmission rates have been reduced to less than 1%. If you decide to use anti-HIV therapy, your regimen will most likely include AZT.

Nevirapine (Viramune) has also been shown to reduce mother-to-child transmission, but it is not FDA-approved for use to reduce the risk of mother-to-child transmission. Studies have included a single dose of nevirapine given to the mother when she goes into labor. The baby is given a single dose based on weight soon after birth. There are concerns about using nevirapine that you should discuss with your doctor before using it. See the box *Nevirapine Warning* on page 9.

Can I breastfeed my baby?

HIV is present in breast milk, and researchers estimate a 29% HIV transmission rate from HIV-positive mothers who consistently breastfeed their children. The most recent information suggests that the risk of HIV transmission from breastfeeding is highest in the early months after birth. The US Public Health Service recommends that HIV-positive women do not breastfeed their children and recommend formula feeding.

For several reasons, formula feeding may not be an option for some women. In this situation, there are alternatives such as heat treatment of breast milk, breast milk banks, or using animal milk such as cow, goat or sheep. If formula feeding isn't an option for you, talk with a counselor, healthcare worker or nurse. They can provide information on various infant-feeding options, the risks and benefits, and guidance on selecting the best option for you and your baby. See the Resource List on page 10 for information on milk banks in the U.S.



frequently asked questions about HIV and pregnancy ...

How is HIV passed to the baby?

HIV can only be passed from mother to child if the *mother* is HIV-positive. If the father is HIV-positive and the mother is not, a baby cannot get HIV from its father. If a woman is HIV-positive, transmission can occur at three points:

- while the baby is in the uterus (*intrauterine*);
- during labor and delivery (when the baby is being born); or
- during breastfeeding (HIV is found in breast milk).

The most common routes of transmission are during labor and delivery and during breastfeeding. There are several factors that can impact the risk of transmission.

FACTORS THAT CAN IMPACT

Viral load

Probably the strongest factor that can affect transmission is the mother's viral load. Viral load is the amount of HIV found in about a teaspoon of blood. A viral load test will be done when you're first diagnosed with HIV and at least every three months after that. Women with more advanced HIV, high viral load and/or low CD4+ cell counts are more likely to pass HIV to their babies. The goal of HIV treatment is to reduce viral load to as low as possible, preferably to undetectable levels or below 50 copies/ml. If a mother's viral load is undetectable when she goes into labor, the risk of transmission is almost zero.

Overall health of the mother

Regardless of a woman's HIV status, her overall health is important for a healthy pregnancy and delivery. This includes proper nutrition; getting enough exercise and rest; quitting smoking; avoiding caffeine, street drugs and alcohol; and getting prenatal care. In addition, many of these negative factors, such as smoking while pregnant, can lead to premature birth or low birth weight. We know from research that in both situations the baby is more at risk for HIV infection. Therefore, it is important for the mother to take care of herself, as her baby's health is dependent on her health.

Time of ruptured membranes

The time between when the water breaks and the actual delivery is called "duration of ruptured membranes." The longer this time is the greater the risk of passing HIV. Most doctors will try to keep this time period to less than four hours. Research shows that if it goes over four hours, then the baby is exposed to HIV longer and there's a greater likelihood of transmission. Induced rupturing of the water bag (also called induced labor) should be avoided whenever possible.

Co-infections

It is important that you're screened *and* treated early on in your pregnancy for any sexually transmitted diseases (STDs) or opportunistic infections (OIs). Having another infection—such as hepatitis C, herpes or other STD—may increase the risk of passing HIV to your baby.

Women who are co-infected with hepatitis C are twice as likely to pass HIV to their infants. Many women living with HIV are also living with genital herpes. It is common for women to have a herpes outbreak during delivery. This can increase the risk of HIV transmission as the sores have high levels of HIV. In addition, there is a risk of passing herpes to the infant. If a woman has a severe HIV-related OI, such as tuberculosis or *Pneumocystis jiroveci* pneumonia (PCP), there's also a risk of increased HIV transmission.

THE RISK OF TRANSMISSION

Access to prenatal care with an HIV specialist

Prenatal care is the healthcare that a woman receives during her pregnancy, before the baby's birth. It includes:

- education and counseling on managing pregnancy;
- tests necessary to track the mother's and baby's health;
- nutrition and exercise to maintain good health and to gain enough weight to provide nourishment to both mother and baby; and
- meetings with doctors: obstetricians (OB), gynecologists (GYN), and perinatologists—those who specialize in the study of the life and development of the baby during pregnancy.



Prenatal care should start as soon as your pregnancy is suspected. However, it is also never too late to seek out and begin prenatal care. The baby's major organs develop during the first trimester of pregnancy (first 14 weeks). Prenatal care is critical during this time to check on the health of the developing baby and identify development problems early on. After the first visit, prenatal appointments usually continue monthly until the beginning of the eighth month. At the eighth month, visits every two weeks is usual; and at month nine, visits become weekly.

For women living with HIV, prenatal care is one of the most important steps to a healthy pregnancy and safe delivery. It is also wise to have your primary HIV

doctor involved in your care. Ideally, your primary HIV doctor has experience working with pregnant women and women considering pregnancy.

This is also a time to talk with your primary HIV doctor about your HIV health and any concerns you may have with your anti-HIV regimen, side effects, etc. It's also a good time to consult with your pharmacist and prenatal team about the impact of medications on your developing baby. Ideally, you will want to have your primary HIV doctor, prenatal team and any other social support—like a peer advocate—communicating and working together for the health of you and your baby.



a baby is on the way ...

Appropriate HIV care and treatment

Finding a healthcare team that supports your decisions and a personal support system to help you along the way are key to a healthy pregnancy and safe delivery for both you and your baby. This includes finding an obstetrician that has experience working with HIV-positive women considering pregnancy, getting regular and good prenatal care, monitoring and managing your HIV disease, and screening for and treating any STDs or OIs earlier rather than later in your pregnancy.

Making a decision about anti-HIV treatment

During the first trimester, if no urgent medical reason exists to begin anti-HIV therapy, it may be beneficial to delay therapy until after 12–14 weeks of pregnancy. There are two main reasons for waiting until the second trimester. First, “morning sickness” (nausea common in the first trimester) may make it difficult to keep medications down and can make adherence to regimens especially difficult. Waiting until the second trimester, when morning sickness usually subsides, may ease the difficulty of taking medicines.

Second, the effects of anti-HIV drugs on the baby during the first trimester are unknown. The baby completes the development of most of its organs at twelve weeks. So, many think it’s best to wait until organ development is complete before starting therapy. However, women who feel it’s important to start therapy earlier should follow their instincts and will not be denied therapy.

For women who already take therapy, stopping therapy during the first trimester to allow for organ development can cause the mother’s viral load to rebound, which may lead to increased transmission risk. On the other hand, continuing the regimen throughout the first trimester may negatively effect the baby’s development. The decision around starting or stopping will vary from person to person. Discuss what would be the best decision for you with your doctor.

If you stop anti-HIV therapy, discuss with your doctors how to do this safely. Regardless of your decision to use anti-HIV drugs during pregnancy, prenatal care and close monitoring of health and lab work (including CD4+ cell counts and viral load) is important.

Making a decision about delivery

Delivering your baby is a personal and emotional experience and can be very different for each woman. For women living with HIV, this is a very complicated issue. It is best to work with your doctor when considering which mode of delivery will help reduce the risk of transmission to your baby. There are two types of delivery: *Caesarean section* (C-section) and *vaginal delivery*.

C-section is a major operation that requires stitches after cutting through and separating the mother’s stomach muscles and uterus to deliver the baby. As with any major operation, a C-section—including elective ones—is not without risk. C-sections pose additional risks to mothers (such as post-surgery bleeding or infections). These risks should be weighed against the benefits of C-sections. Elective or scheduled C-sections are done before labor begins and before the mother’s “water” (the membrane that surrounds the baby) breaks. This reduces the baby’s contact with the mother’s blood. In general, a scheduled C-section may most benefit a woman who has a high viral load or who has an STD such as herpes or hepatitis C, as it will reduce the time of exposing HIV to the infant.

A vaginal delivery is the birth of the baby through the vagina. For women whose overall health is good and who have a low or undetectable viral load, a vaginal delivery is a viable option.

Either choice is a good choice, as long as it’s your own and you work with your doctor to decide which mode will ensure the safest delivery for you and your baby.



a baby is on the way ...

Nutrition and exercise

The baby's health and nutrition is dependent on the mother's health. Poor nutrition and insufficient weight gain in the mother can increase the risk of a premature or low birth weight baby, thus increasing the risk of passing HIV. Body and weight changes do occur during pregnancy, and it's important the woman gains enough weight to provide nourishment for herself and her baby. While the average weight gain during pregnancy is 25–30 pounds, this will vary based on a woman's build and her metabolism.

Positive women may have trouble gaining weight and may gain less than what is usually recommended during pregnancy. Common side effects from anti-HIV medication can make gaining weight difficult or even cause weight loss.

At your first prenatal visit, a careful assessment of your nutritional needs will be done. Pregnancy increases the need for calories and protein. Folic acid, iron, calcium and fluids are all important to the baby's development. Proper levels of each should be included in the mother's diet. Most women are recommended to take a folic acid supplement at least three months before getting pregnant or as soon as they find out that they are pregnant.

Regular exercise is important. It strengthens and tones muscles, making pregnancy, labor and delivery easier to experience. Swimming and walking are beneficial since they place little strain on muscles. Good rest is also necessary. Pregnant women should check themselves carefully and not overextend themselves. At least eight hours of sleep a night is recommended, and many women will find they need even more.



Learning if your baby is HIV-positive or -negative

It's natural to want to know right away whether your baby is infected with HIV. Still, it often takes at least three months and as long as eighteen to definitively learn the HIV status of your baby. During this time, your baby will receive a number of blood tests.

All babies born to HIV-positive mothers, including babies who are *not* HIV-infected, will test positive for HIV antibodies at birth and for many months afterward. This is because a baby is born with its mother's antibodies. It takes time for the baby to lose them and develop his or her own. Your baby will be tested for HIV at birth and then at one month and at three months.

If you're not breastfeeding and all of these tests come back negative, your baby is not infected with HIV. After the baby is born, your doctor will likely advise that he or she take anti-HIV drugs for 4–6 weeks. This will most likely be AZT in liquid form taken two or four times a day. Studies suggest that this use of anti-HIV medicine for the first few weeks of life plays some role in further lowering the risk of HIV infection in your baby.

If the tests come back positive and your baby is determined to be infected with HIV, your doctor will discuss treatment and care options for your child. See the Resource List on page 10 for organizations with information on pediatric HIV/AIDS.

Bloodless C-section

A "bloodless C-section" or "bloodless delivery" is another option that women may choose. It is an elective C-section where the mother's blood vessels are cauterized so the baby isn't exposed to the mother's blood. Cauterization uses an agent (such as heat, cold or electricity) to scar and burn blood vessels as they're being cut so they don't bleed. Once the mother's blood vessels are cauterized, the amniotic sac is opened and the baby is removed. Experimentation with bloodless C-section continues in search of a way to further reduce the contact with maternal blood and fluids. The benefits of this procedure in terms of preventing HIV transmission and its risks to the mother have not been fully explored. The procedure is expensive (around \$8,000) and may not be covered by insurance.



Managing morning sickness

Nausea or morning sickness during pregnancy is normal and usually poses a problem only during the first trimester. If these conditions persist into the second trimester (weeks 13–26), or if you cannot hold food down at all or lose weight, talk with your doctor at once. This could be a sign of a more significant problem. A few tips on morning sickness:

- Eat small, frequent meals every two or three hours, even through the night.
- Keep dry crackers beside your bed and eat a couple before getting up in the morning. It also sometimes helps to eat crackers about an hour before your first drug dose of the day.
- Eat lots of carbohydrates, like dry toast, bananas, baked potatoes, rice and whole grain breakfast cereals.
- Flat soda and sweet juices in the morning can help nausea.
- Ginger tea with honey and candied ginger may help.

medications and procedures to

There are several prenatal procedures and medications that can harm the mother and/or the baby’s development. It’s important to work closely with your doctor to carefully weigh the risks and the benefits. In addition, certain health and nutrition issues are important to consider.

The following tests should be avoided unless they are essential:

- Amniocentesis tests for genetic defects in the baby. This is done with a needle inserted through the mother’s abdomen and into her uterus.
- CVS (*chorionic villus sampling*) tests for genetic abnormalities in the baby and for inherited disorders. This is done by inserting a speculum into the uterus and taking a small sample from the forming placenta.
- Cordocentesis or fetal blood sampling (FBS)—also known as PUBS (*percutaneous umbilical blood sampling*)—is a procedure that removes a small amount of blood from the fetus during pregnancy. FBS is performed to diagnose, treat and monitor various fetal problems such as severe fetal anemia, genetic or chromosome abnormalities, fetal infections, or to give certain medications to the fetus. Fetal scalp sampling is another type of procedure used for similar reasons when a small amount of blood is taken from the infant’s scalp during labor.
- Internal fetal and labor monitoring (external fetal monitoring such as ultrasound is safe)

Health and nutrition

- Avoid the following:
 - uncooked or undercooked meat,
 - cat feces, cat litter and soil that contains cat feces,
 - unpasteurized dairy products, and
 - hot tubs, saunas, or exposure to illnesses that can cause fevers or high body temperatures.
- Cut back on caffeine (including coffee, tea, soft drinks, and herbal products that contain caffeine).



consider during pregnancy

Medications for treating HIV disease

The following is a list of medications used to treat HIV and common HIV-related illnesses that should be used with caution or not used at all during pregnancy.

The following anti-HIV drugs are contraindicated for use during pregnancy:

- **Efavirenz (Sustiva)**
Efavirenz can cause brain damage to the infant. It should not be used at all during pregnancy and should be stopped immediately if you plan to get pregnant or find out that you are pregnant.
- **Hydroxyurea**
This drug is not commonly used to treat HIV anymore. However, it should not be used during pregnancy or by the man while trying to conceive.
- **ddI (Videx) and d4T (Zerit)**
When these drugs are used together, they can cause excess lactate leading to potential liver damage (*lactic acidosis*). This risk is increased in pregnant women. This can be dangerous for both the mother and the developing baby, so they should not be used during pregnancy.
- **Liquid form of amprenavir (Agenerase)**
One of the components of this form of Agenerase is unable to be broken down by pregnant women and young children. Agenerase in capsule form is safe to take.

The following anti-HIV drugs can be used if and when the benefits outweigh the risks. However, close monitoring is recommended.

- **Atazanavir and indinavir**
Atazanavir (Reyataz) and indinavir (Crixivan) can increase levels of bilirubin (a chemical produced in the liver). Serious elevations can cause liver dysfunction, which can impact both the mother and baby. These drugs can be used during pregnancy, but extra monitoring may be needed. If you have hepatitis C or any other liver problems, talk with your doctor about taking these protease inhibitors.
- **Protease inhibitors**
Protease inhibitors and pregnancy have both been associated with diabetes and/or elevated glucose levels. If you take protease inhibitors during your pregnancy, make sure your doctor closely checks your glucose levels.

Medications for opportunistic infections and other illnesses

The following medicines are contraindicated for use during pregnancy:

- **Azole drugs**
Azole drugs (such as fluconazole or itraconazole) are used to treat and prevent yeast/fungal infections and thrush. They potentially cause birth defects and should not be taken orally. It is very common for pregnant women to get yeast infections, so talk with your doctor about topical options for prevention and treatment.
- **Intravaginal 5-fluorouracil**
Intravaginal 5-fluorouracil (5-FU) is used to treat cervical dysplasia (abnormal cells in, on and/or around the cervix, most commonly caused by human papillomavirus) is not recommended during pregnancy.
- **Live vaccines**
Live vaccines including measles, mumps and rubella should not be used during pregnancy.

Nevirapine Warning

Women with CD4+ cell counts above 250 are not recommended to take nevirapine (Viramune). There is a significant risk of liver toxicity. For women with CD4+ cell below 250, nevirapine appears to be safe. Talk with your doctor about an alternative drug if your CD4+ cell count is above 250.

Resource List



W.O.R.L.D.

(Women Organized to Respond to Life-threatening Diseases)

414 Thirteenth Street, 2nd Floor, Oakland, CA 94612
1-510-986-0340

WORLD publishes a monthly newsletter for women with HIV and has a peer advocate program, treatment training program, and retreats for HIV-positive women.

National Women's Health Information Center

1-800-994-WOMAN

This government-sponsored hotline provides information on women's health issues, including HIV and pregnancy.

General HIV Information Hotlines

CDC National AIDS Hotline

1-800-342-AIDS

AIDS information and referrals, 24 hours a day, 7 days a week.

HIV/AIDS Treatment Information Service

1-800-HIV-0440

This hotline answers questions about HIV treatment and distributes the Federal Guidelines on HIV Treatment free of charge.

HIV/Pregnancy Information

Antiviral Pregnancy Registry

PO Box 13398

Research Triangle Park, NC 27709-3398

1-800-258-4263

Kept records document whether HIV drugs cause problems in pregnancy.

Test Positive Aware Network newsletter

1-773-989-9400

Bi-monthly newsletter for people living with HIV. Ask for the issues titled, *She's Having a Baby*, and *HIV & Pregnancy*.

www.who.int

The publication, *HIV and Infant Feeding: A Guide for Healthcare Managers and Supervisors*, Geneva, 2003, is available online at www.who.int/child-adolescent-health/publications/NUTRITION/ISBN_92_4_159123_4.htm.

Human Milk Banks

Mother's Milk Bank—Valley Medical Center

751 South Bascom

San Jose, CA 95128

1-408-998-4550

Mother's Milk Bank—Columbia P/SL Hospital

1719 E. 19th Avenue

Denver, CO 80218

1-303-869-1888

For all milk banks, donors are screened volunteers for their health history and given blood tests. Breast milk is given only by prescription and can be delivered anywhere in the US by air shipping. Milk costs \$2.50/ounce, not including shipping fee. Medi-Cal and Medicaid covers the total cost of milk. Some private insurance companies are beginning to cover it as well.

Research/Clinical Trials Hotlines

AIDS Clinical Trial Information Service

1-800-TRIALS A

A hotline with information about pediatric and adult clinical trials and specific trails in your area, including studies of AIDS drugs in pregnancy.

Websites

www.womenchildrenhiv.org

Online site provides resources on the prevention and treatment of HIV infection in women and children targeted at health workers, program managers, and policymakers in resource-poor settings.

www.i-base.org

The publication, *HIV Pregnancy and Women's Health*, Spring 2005, is available online.

www.thewellproject.org

The Well Project is a website created by and for women living with HIV/AIDS.