

HIV During Pregnancy, Labor and Delivery, and After Birth

Health Information for HIV Positive Pregnant Women

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Fact Sheets



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HIV During Pregnancy, Labor and Delivery, and After Birth

This series of fact sheets is intended for women who are HIV positive and pregnant or have recently given birth. These fact sheets describe the steps an HIV positive pregnant woman can take to preserve her health and prevent transmission of HIV to her baby.

These fact sheets are designed as a series, but can also be used as stand-alone documents. The information in these fact sheets is based on the U.S. Public Health Service's *Recommendations for Use of Antiretroviral Drugs in Pregnant HIV-Infected Women for Maternal Health and Interventions to Reduce Perinatal HIV Transmission in the United States* and *Guidelines for the Use of Antiretroviral Agents in Pediatric HIV Infection* (available at http://aidsinfo.nih.gov/guidelines).

Table of Contents

- HIV Testing and Pregnancy
- Treatment Regimens for HIV Positive Pregnant Women
- Safety and Toxicity of Anti-HIV Medications During Pregnancy
- Delivery Options for HIV Positive Pregnant Women
- HIV Positive Women and Their Babies After Birth



HIV Testing and Pregnancy

I am pregnant, and I may have HIV. Will I be tested for HIV when I visit a doctor?

In most cases, health care providers cannot test you for HIV without your permission. However, the U.S. Public Health Service recommends that all pregnant women be tested. If you are thinking about being tested, it is important to understand the different ways **perinatal HIV testing** is done. There are two main approaches to HIV testing in pregnant women: *opt-in* and *opt-out testing*.

In *opt-in testing*, a woman cannot be given an HIV test unless she specifically requests to be tested. Often, she must put this request in writing.

In *opt-out testing*, health care providers must inform pregnant women that an HIV test will be included in the standard group of tests pregnant women receive. A woman will receive that HIV test unless she specifically refuses. The **CDC** currently recommends that health care providers adopt an opt-out approach to perinatal HIV testing.

What are the benefits of being tested?

By knowing your HIV status, you and your doctor can decide on the best treatment for you and your baby and can take steps to prevent **mother-to-child transmission** of HIV. It is also important to know your HIV status so that you can take the appropriate steps to avoid infecting others (see <u>Understanding HIV Prevention Fact</u> <u>Sheet</u>).

What happens if I agree to be tested?

If you agree to be tested, your doctor should counsel you before the test about the way your life may change after you receive the test results. If the test indicates that you have HIV, you should be given a second test to confirm the results. If your second test is positive for HIV, you and your doctor will decide which treatment options are best for you and your baby (see <u>Treatment Regimens for</u> <u>HIV Positive Pregnant Women Fact Sheet</u>). If the test indicates that you do not have HIV, you may receive counseling on HIV prevention.

Terms Used in This Fact Sheet:

CDC (Centers for Disease Control and Prevention): an agency of the U.S. Federal government that focuses on disease prevention and control, environmental health, and health promotion and education. <u>http://www.cdc.gov</u>.

Mother-to-child transmission: the passage of HIV from an HIV positive mother to her infant. The infant may become infected while in the womb, during labor and delivery, or through breastfeeding. Also known as perinatal transmission.

Perinatal HIV testing: testing for HIV during pregnancy or during labor and delivery.

What happens if I refuse to be tested?

If you decide that you do not want to be tested for HIV, your doctor may offer you counseling about the way HIV is transmitted and the importance of taking steps to prevent HIV transmission. He or she may also talk to you about the importance of finding out your HIV status so that you can take steps to prevent your baby from becoming infected.

Will my baby be tested for HIV?

Health care providers recommend that all babies born to HIV positive mothers be tested for HIV. However, states differ in the ways they approach HIV testing for babies.

- some states require that babies receive a mandatory HIV test if the status of the mother is unknown
- some states require that health care providers test babies for HIV unless the mother refuses
- some states are only required to offer an HIV test to pregnant women (not their babies), which they can either accept or refuse
- some states have no specific requirements about testing pregnant women or their babies.

How can I find out the testing policies of my state?

The U.S. Department of Health and Human Services (HHS) can provide you with HIV testing information for your state. Contact HHS at 1–877–696–6775 or 202–619–0257.

For more information:

Contact your doctor or an AIDS*info* Health Information Specialist at 1–800–448–0440 or <u>http://aidsinfo.nih.gov</u>.

This information is based on the U.S. Public Health Service's *Recommendations for Use of Antiretroviral Drugs in Pregnant HIV-Infected Women for Maternal Health and Interventions to Reduce Perinatal HIV Transmission in the United State* (available at http://aidsinfo.nih.gov).



Treatment Regimens for HIV Positive Pregnant Women

I am HIV positive and pregnant. Should I take anti-HIV medications?

Yes. If you are HIV positive and pregnant, it is recommended that you take anti-HIV medications to prevent your baby from becoming infected with HIV, and in some cases, for your own health. Anti-HIV medications are recommended for all pregnant women regardless of **CD4 count** and **viral load**. HIV treatment is an important part of preventing your baby from becoming infected with HIV and maintaining your health.

When should I consider starting anti-HIV treatment?

When you start treatment will depend mostly on whether you need treatment only to prevent your baby from becoming infected with HIV or if you also need treatment for your own health. In general, it is recommended that pregnant women who are starting therapy for their own health be treated as soon as possible, including in the first trimester. For women who are beginning therapy only to prevent **mother-to-child transmission**, delaying anti-HIV medication until after the first trimester can be considered. You should discuss when to begin treatment with your doctor.

How do I find out which HIV treatment regimen is best for me?

Decisions about which HIV treatment regimen you will start should be based on many of the same factors that women who are not pregnant must consider. These factors include:

- risk that the HIV infection may become worse
- risks and benefits of delaying treatment (see <u>Starting</u> <u>Anti-HIV Medications Fact Sheet</u>)
- potential drug toxicities and interactions with other drugs you are taking (see <u>Safety and Toxicity of Anti-HIV Medications during Pregnancy Fact Sheet</u>)

Terms Used in This Fact Sheet:

CD4 count: CD4 cells, also called T cells or CD4⁺ T cells, are white blood cells that fight infection. HIV destroys CD4 cells, making it harder for your body to fight infections. A CD4 count is the number of CD4 cells in a sample of blood.

Drug resistance testing: a laboratory test to determine if an individual's HIV strain is resistant to any anti-HIV medications. HIV can mutate (change form), resulting in HIV that cannot be controlled with certain medications.

Highly active antiretroviral therapy (HAART): the name given to treatment regimens that aggressively suppress HIV replication and progression of HIV disease. The usual HAART regimen combines three or more anti-HIV drugs.

Intravenous (IV): the administration of fluid or medicine into a vein.

Mother-to-child transmission: the passage of HIV from an HIV positive mother to her infant. The infant may become infected while in the womb, during labor and delivery, or through breastfeeding. Also known as perinatal transmission.

Viral load: the amount of HIV in a sample of blood.

- the need to adhere to a treatment regimen closely (see **Fact Sheet: What is Treatment Adherence?**)
- the results of drug resistance testing

In addition to these factors, pregnant women must consider the following issues:

- benefit of lowering viral load and reducing the risk of mother-to-child transmission of HIV
- unknown long-term effects on your baby if you take anti-HIV medications during your pregnancy
- information available about the use of anti-HIV medications during pregnancy

You should discuss your treatment options with your doctor so that together you can decide which treatment regimen is best for you and your baby.



Treatment Regimens for HIV Positive Pregnant Women (continued)

What treatment regimen should I follow during my pregnancy if I have never taken anti-HIV medications?

Your best treatment options depend on when you were diagnosed with HIV, when you found out you were pregnant, at what point you sought medical treatment during your pregnancy, and whether you need treatment for your own health. Women who are in the first trimester of pregnancy and who do not have symptoms of HIV disease may consider delaying treatment until after 10 to 12 weeks into their pregnancies. After the first trimester, pregnant women with HIV should receive at least AZT (Retrovir or zidovudine); your doctor may recommend additional medications depending on your CD4 count, viral load, and drug resistance testing.

I am currently taking anti-HIV medications, and I just learned that I am pregnant. Should I stop taking my medications?

Do not stop taking any of your medications without consulting your doctor first. Stopping HIV treatment could lead to problems for you and your baby. If you are taking anti-HIV medications and your pregnancy is identified during the first trimester, talk with your doctor about the risks and benefits of continuing your current regimen. Your doctor may recommend that you change the medications you take. If your pregnancy is identified after the first trimester, it is recommended that you continue with your current treatment. No matter what HIV treatment regimen you were on before your pregnancy, it is generally recommended that AZT become part of your regimen.

Will I need treatment during labor and delivery?

Most mother-to-child transmission of HIV occurs around the time of labor and delivery. Therefore, HIV treatment during this time is very important for protecting your baby from HIV infection. Several treatments can be used together to reduce the risk of transmission to your baby.

- 1. **Highly active antiretroviral therapy (HAART)** is recommended even for HIV-infected pregnant women who do not need treatment for their own health. If possible, HAART should include AZT (Retrovir or zidovudine).
- 2. During labor and delivery, you should receive intravenous (IV) AZT.
- 3. Your baby should take AZT (in liquid form) every 6 hours for 6 weeks after birth.

If you have been taking any other anti-HIV medications during your pregnancy, your doctor will probably recommend that you continue to take them on schedule during labor.

Better understanding of HIV transmission has contributed to dramatically reduced rates of mother-to-child transmission of HIV. Discuss the benefits of HIV treatment during pregnancy with your doctor; these benefits should be weighed against the risks to you and to your baby.

For more information:

Contact your doctor or an AIDS*info* Health Information Specialist at 1–800–448–0440 or <u>http://aidsinfo.nih.gov</u>.



Safety and Toxicity of Anti-HIV Medications During Pregnancy

I am HIV positive and pregnant. Are there any anti-HIV medications that may be dangerous to me or my baby during my pregnancy?

Yes. Although information on anti-HIV medications in pregnant women is limited, enough is known to make recommendations about medications for you and your baby. However, the long-term effects of babies' exposure to anti-HIV medications *in utero* are unknown. Talk to your doctor about which medications may be harmful during your pregnancy and what medication and dose changes are possible.

In general, **protease inhibitors (PIs)** are associated with increased levels of blood sugar (hyperglycemia), development of diabetes mellitus or worsening of diabetes mellitus symptoms (see <u>Hyperglycemia Fact Sheet</u>), and **diabetic ketoacidosis**. Pregnancy is also a risk factor for hyperglycemia, but it is not known whether PI use increases the risk for pregnancy-associated hyperglycemia or gestational diabetes.

Two **non-nucleoside reverse transcriptase inhibitors** (NNRTIs), Rescriptor (delavirdine) and Sustiva (efavirenz),

are not recommended for the treatment of HIV-infected pregnant women. Use of these medications during pregnancy may lead to birth defects. Another NNRTI, Viramune (nevirapine), may be part of your HIV treatment regimen. Long-term use of Viramune may cause negative side effects, such as exhaustion or weakness; nausea or lack of appetite; yellowing of eyes or skin; or signs of liver toxicity, such as severe skin rash, chills, fever, sore throat, or other flu-like symptoms, liver tenderness or enlargement or elevated liver enzyme levels (see Hepatotoxicity Fact Sheet). These negative side effects are not normally seen with short-term use (one or two doses) of Viramune during pregnancy. However, because pregnancy and early symptoms of liver toxicity can be similar, your doctor should monitor you closely while you are taking Viramune. Also, Viramune should be used with caution in women who have never received HIV treatment and who have CD4 counts greater than 250 cells/mm³. Liver toxicity has occurred more frequently in these patients.

Terms Used in This Fact Sheet:

Diabetic ketoacidosis: a complication of diabetes in which sugar is not broken down for energy and fat is broken down instead. This leads to an unhealthy buildup of ketones (fat by-products).

Entry inhibitor: class of anti-HIV medication. Entry inhibitors work by preventing HIV from entering a cell.

Integrase inhibitor: class of anti-HIV medication. Integrase inhibitors prevent the HIV integrase protein from inserting HIV's genetic information into an infected cell's own DNA.

In utero: the time an unborn baby is in its mother's uterus.

Mitochondrial toxicity: damage to the mitochondria (rodlike structures that serve as a cell's powerhouse) that can cause problems in the heart, nerves, muscles, pancreas, kidneys, and liver.

Non-nucleoside reverse transcriptase inhibitor (NNRTI): class of anti-HIV medication. NNRTIs work by blocking reverse transcriptase, a protein that HIV needs to make copies of itself.

Nucleoside reverse transcriptase inhibitor (NRTI): class of anti-HIV medication. NRTIs are faulty versions of the building blocks (nucleosides) used by reverse transcriptase, a protein that HIV needs to make copies of itself.

Protease inhibitor (PI): class of anti-HIV medication. PIs work by blocking protease, a protein that HIV needs to make copies of itself.

Nucleoside reverse transcriptase inhibitors (NRTIs) may cause mitochondrial toxicity, which may lead to a buildup of lactic acid in the blood. This buildup is known as hyperlactatemia or lactic acidosis (see Lactic Acidosis Fact Sheet). This toxicity may be of particular concern for pregnant women and babies exposed to NRTIs *in utero*.

There is very little known about the use of the **entry inhibitors** Fuzeon (enfuvirtide) and Selzentry (maraviroc) and the **integrase inhibitor**, Isentress (raltegravir), during pregnancy.

For more information:

Contact your doctor or an AIDS*info* Health Information Specialist at 1–800–448–0440 or <u>http://aidsinfo.nih.gov</u>.

This information is based on the U.S. Public Health Service's *Recommendations for Use of Antiretroviral* Drugs in Pregnant HIV-Infected Women for Maternal Health and Interventions to Reduce Perinatal HIV Transmission in the United States (available at http://aidsinfo.nih.gov).



Delivery Options for HIV Positive Pregnant Women

I am HIV positive and pregnant. What delivery options are available to me when I give birth?

Depending on your health and treatment status, you may plan to have either a cesarean (also called c-section) or a vaginal delivery. The decision of whether to have a cesarean or a vaginal delivery is something that you should discuss with your doctor during your pregnancy.

How do I decide which delivery option is best for my baby and me?

It is important that you discuss your delivery options with your doctor as early as possible in your pregnancy so that he or she can help you decide which delivery method is most appropriate for you.

Cesarean delivery is recommended for an HIV positive mother when:

- her viral load is unknown or is greater than 1,000 copies/mL at 36 weeks of pregnancy
- she has not taken any anti-HIV medications or has only taken AZT (Retrovir or zidovudine) during her pregnancy
- she has not received **prenatal** care until 36 weeks into her pregnancy or later

To be most effective in preventing transmission, the cesarean should be scheduled at 38 weeks or should be done before the **rupture of membranes** (also called water breaking).

Vaginal delivery is recommended for an HIV positive mother when:

- she has been receiving prenatal care throughout her pregnancy
- she has a viral load less than 1,000 copies/mL at 36 weeks, and

Vaginal delivery may also be recommended if a mother has ruptured membranes and labor is progressing rapidly.

Terms Used in This Fact Sheet:

Intravenous (IV): the administration of fluid or medicine into a vein.

Mother-to-child transmission: the passage of HIV from an HIV positive mother to her infant. The infant may become infected while in the womb, during labor and delivery, or through breastfeeding. Also known as perinatal transmission.

Prenatal: the time before birth.

Rupture of membranes: when the sac containing the unborn baby bursts or develops a hole. Also known as "water breaking."

What are the risks involved with these delivery options?

All deliveries have risks. The risk of **mother-to-child transmission** of HIV may be higher for vaginal delivery than for a scheduled cesarean. For the mother, cesarean delivery has an increased risk of infection, anesthesiarelated problems, and other risks associated with any type of surgery. For the infant, cesarean delivery has an increased risk of infant respiratory distress.

Is there anything else I should know about labor and delivery?

Intravenous (IV) AZT should be started 3 hours before a scheduled cesarean delivery and should be continued until delivery. IV AZT should be given throughout labor and delivery for a vaginal delivery. It is also important to minimize the baby's exposure to the mother's blood. This can be done by avoiding any invasive monitoring and forceps- or vacuum-assisted delivery.

All babies born to HIV positive mothers should receive anti-HIV medication to prevent mother-to-child transmission of HIV. The usual treatment for infants is 6 weeks of AZT; sometimes, additional medications are also given (see the <u>HIV Positive Women and Their Babies</u> <u>After Birth Fact Sheet</u>).

For more information:

Contact your doctor or an AIDS*info* Health Information Specialist at 1–800–448–0440 or <u>http://aidsinfo.nih.gov</u>.

This information is based on the U.S. Public Health Service's *Recommendations for Use of Antiretroviral Drugs in Pregnant HIV-Infected Women for Maternal Health and Interventions to Reduce Perinatal HIV Transmission in the United States* (available at http://aidsinfo.nih.gov).



HIV Positive Women and Their Babies After Birth

I am an HIV positive pregnant woman, and I am currently on an HIV regimen. Will my regimen change after I give birth?

Many women who are on an HIV treatment regimen during pregnancy decide to stop or change their regimens after they give birth. You and your doctor should discuss your **postpartum** treatment options during your pregnancy or shortly after delivery. Don't stop taking any of your medications without consulting your doctor first. Stopping HIV treatment could lead to problems.

How will I know if my baby is infected with HIV?

Babies born to HIV positive mothers are tested for HIV differently than adults. Adults are tested by looking for antibodies to HIV in their blood. A baby keeps antibodies from its mother, including antibodies to HIV, for many months after birth. Therefore, an antibody test given before the baby is 18 months old may be positive even if the baby does NOT have HIV infection. For the first 18 months, babies are tested for HIV directly, and not by looking for antibodies to HIV. When babies are more than 18 months old, they no longer have their mother's antibodies and can be tested for HIV using the antibody test.

Preliminary HIV tests for babies are usually performed at three time points:

- birth to 14 days
- at 1 to 2 months of age
- at 3 to 6 months of age

If babies test *negative* on two of these preliminary tests, they should be given an HIV antibody test between 12-18 months. Babies who test negative for HIV antibodies at this time are not HIV infected.

Babies are considered HIV positive if they test *positive* on two of these preliminary HIV tests. Babies who test positive for HIV antibodies will need to be retested at 15 to 18 months. At 18 months, babies should have an HIV

Terms Used in This Fact Sheet:

Adherence: how closely you follow, or adhere to, your treatment regimen. This includes taking the correct dose at the correct time as prescribed by your doctor.

Anemia: a condition in which there are too few red blood cells in the blood. Without enough red blood cells, not enough oxygen gets to tissues and organs. Symptoms of anemia include fatigue, chest pain, and shortness of breath.

CDC (Centers for Disease Control and Prevention): an agency of the U.S. Federal government that focuses on disease prevention and control, environmental health, and health promotion and education. <u>http://www.cdc.gov</u>.

Complete blood count (CBC): a routine blood test that measures white and red blood cell counts, platelets (cells involved in blood clotting), hematocrit (amount of iron in the blood), and hemoglobin (an iron-containing substance in red blood cells). Changes in the amounts of each of these may indicate infection, anemia, or other problems.

Mother-to-child transmission: the passage of HIV from an HIV positive mother to her infant. The infant may become infected while in the womb, during labor and delivery, or through breastfeeding. Also known as perinatal transmission.

Oral: to be taken by mouth.

P. carinii/jiroveci pneumonia (PCP): a common opportunistic infection in which fluid develops in the lungs. It is caused by the fungus Pneumocystis carinii/jiroveci. PCP is considered an AIDS-defining illness by the CDC.

Postpartum: the time after giving birth.

antibody test to confirm HIV infection. A positive HIV antibody test given after 18 months of age confirms HIV infection in children.

Are there any other tests my baby will receive after birth?

Babies born to HIV positive mothers should have a **complete blood count (CBC)** after birth. They should also be monitored for signs of **anemia**, which is the main negative side effect caused by the 6-week AZT (Retrovir, or zidovudine) regimen infants should take to reduce the risk of HIV infection. They may also undergo other routine blood tests and vaccinations for babies.

This information is based on the U.S. Public Health Service's *Recommendations for Use of Antiretroviral Drugs in Pregnant HIV-Infected Women for Maternal Health and Interventions to Reduce Perinatal HIV Transmission in the United States* and *Guidelines for the Use of Antiretroviral Agents in Pediatric HIV Infection* (available at <u>http://aidsinfo.nih.gov</u>).



HIV Positive Women and Their Babies After Birth (continued)

Will my baby receive anti-HIV medication?

Yes. It is recommended that all babies born to HIV positive mothers receive a 6-week course of **oral** AZT to help prevent **mother-to-child transmission** of HIV. This oral AZT regimen should begin within 6 to 12 hours after your baby is born. Some doctors may recommend that AZT be given in combination with other anti-HIV medications. You and your doctor should discuss the options to decide which treatment is best for your baby.

In addition to HIV treatment, your baby should also receive treatment to prevent **P. carinii/jiroveci pneumonia** (**PCP**). The recommended treatment is a combination of the medications sulfamethoxazole and trimethoprim.* This treatment should be started when your baby is 4 to 6 weeks old and the 6-week course of AZT is complete. The treatment should continue until your baby is confirmed to be HIV negative. If your baby is HIV positive, he or she will need to take this treatment indefinitely.

What type of medical follow-up should I consider for my baby and me after I give birth?

Seeking the right medical and supportive care services is important for you and your baby's health. These services may include:

- routine medical care
- HIV specialty care
- family planning services
- mental health services
- substance abuse treatment
- case management

Talk to your doctor about these services and any others you may need. He or she should be able to help you locate appropriate resources.

What else should I think about after I give birth?

The **CDC** recommends that women not breastfeed in areas where safe drinking water and infant formula are available (such as the United States). This is recommended to avoid transmission of HIV to infants through breast milk.

Physical and emotional changes during the postpartum period, along with the stresses and demands of caring for a new baby, can make it difficult to follow your HIV treatment regimen. **Adherence** to your regimen is important for you to stay healthy (see <u>Fact Sheet: What</u> <u>is Treatment Adherence</u>?). Other issues you may want to discuss with your doctor include:

- concerns you may have about your regimen and treatment adherence
- feelings of depression (many women have these feelings after giving birth)
- long-term plans for continuing medical care and HIV treatment for you and your baby

For more information about HIV and pregnancy, your doctor can contact the National HIV Telephone Consultation Service (Warmline), a service that provides health care professionals with HIV information. The number is 1–800–933–3413.

If you are interested in joining a pregnancy registry that monitors HIV positive women during their pregnancies and after giving birth, please visit the Food and Drug Administration's Guide to Pregnancy Registries at <u>http://www.fda.gov/womens/registries</u>. Researchers are especially interested in learning more about the effects of anti-HIV drugs during pregnancy. HIV positive pregnant women are therefore encouraged to register with the Antiretroviral Pregnancy Registry at 1–800–258–4263 or <u>http://www.APRegistry.com</u>.

For more information:

Contact your doctor or an AIDS*info* Health Information Specialist at 1–800–448–0440 or <u>http://aidsinfo.nih.gov</u>.

This information is based on the U.S. Public Health Service's *Recommendations for Use of Antiretroviral Drugs in Pregnant HIV-Infected Women for Maternal Health and Interventions to Reduce Perinatal HIV Transmission in the United States* and *Guidelines for the Use of Antiretroviral Agents in Pediatric HIV Infection* (available at <u>http://aidsinfo.nih.gov</u>).

^{*} The combination of sulfamethoxazole and trimethoprim is known by other names. For more information, see the <u>Sulfamethoxazole/</u><u>Trimethoprim Drug Fact Sheet</u>.