



Pregnancy and HIV

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Major advances have been made in the understanding of mother-to-child HIV transmission (sometimes called vertical or perinatal transmission). New information has made it more likely for women living with HIV to give birth to healthy, HIV-uninfected babies. With good prenatal care, the use of anti-HIV therapy and comprehensive health care programs, transmission rates have decreased dramatically.

Having a baby is a very personal decision, as is the way a woman chooses to proceed with her pregnancy. While this may vary from woman to woman, a comprehensive strategy to prevent mother-to-child HIV transmission is made up of four basic building blocks:



The final building block calls for a decision about whether or not to breast-feed the child after delivery.

HIV can be transmitted through breast milk. The most recent information suggests that the risk of HIV transmission from breast-feeding is highest in the early months after birth. Where safe alternatives to breast-feeding are available, women are advised not to breast-feed their children.

This discussion paper guides future and expectant moms through these four areas. It also describes additional care issues for the mother, including the development of a strategy to treat and prevent opportunistic infections during pregnancy. Finally, developing a comprehensive prevention strategy may also be gained by better understanding the factors that influence vertical HIV transmission. The main factors associated with vertical transmission and strategies to lower the risk of transmission are also highlighted.

A note about the structure of this discussion paper: if you've recently found out you're HIV-positive, pregnant or both, you may already feel pretty overwhelmed. You may find all this information a little difficult to get through, especially if you try to take it in all at once. To ease this concern, the document places the most basic and time-sensitive information up front, with supportive and extending materials later. You can read what you want at your own pace and according to your own needs. You might just read one section at a time. We recommend you start with the section on prenatal care. When you're ready, move on to the next section. The material will always be here when you're ready to read more.



- A. Good prenatal care
- B. A comprehensive anti-HIV strategy
- C. A plan for delivery of the baby
- D. A decision about breast-feeding

Perhaps the most important building block is good prenatal care. The importance of receiving good and early prenatal care cannot be overstated. This discussion paper talks a lot about prenatal care and describes what should (and should not) be included for women living with HIV.

The second building block, developing an anti-HIV strategy, may (or may not) include using anti-HIV therapies that decrease the rate of vertical HIV transmission.

The third block requires thoughtful planning about what to do when it's time to deliver the baby (e.g. vaginal delivery vs. elective C-section). Certain kinds of C-sections have been associated with decreased transmission rates. The benefits of C-section need to be considered against its potential risks.



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Pregnancy and HIV

Table of Contents

Basics on HIV and Pregnancy 2

Building Block One:

Prenatal Care 3
 When Should I Begin Receiving Prenatal Care? ... 3
 What Should My Prenatal Care Include? 3
 Are There Prenatal Procedures I Should Avoid? 4
 Other Things to Avoid During Pregnancy? 4
 Domestic Violence During Pregnancy 5
 Just Found Out You're Positive and Pregnant? 5
 What Will Other People Think? 5

Building Block Two:

Anti-HIV Therapy During Pregnancy 6
 Combination Therapy 6
 Starting or Continuing Therapy
 During Pregnancy 7
 One Pill at a Time 8
 Drug Interaction Alert 8
 Managing Morning Sickness 9
 A Few Tips to Deal with Morning Sickness 9
 Vertical Transmission of Drug Resistant HIV 9
 OI Prevention and Treatment 9–10

Building Block Three:

Making a Decision About Delivery 11
 Route of Delivery 11
 Bloodless C-Section 11
 Are C-Sections Always Necessary? 12

Building Block Four:

Making a Decision About Breast-Feeding 12

Additional Factors

Affecting Transmission 13
 Co-Infections 13
 Other Factors 14
 Learning if Your Baby's Positive or Negative 14

Commentary 15

Resource Guide 16

Basics on HIV and Pregnancy

Many women are concerned about the burden that pregnancy may place on their bodies and the effect it may have on HIV disease. However, there's no evidence that pregnancy, by itself, will change the course of HIV disease. It will not *speed up* the rate at which HIV disease progresses.

Similarly, HIV infection doesn't appear to change the way a pregnancy normally proceeds. Severe complications to the mother's and the unborn baby's health can occur if the mother has an HIV-related opportunistic infection, such as *Pneumocystis carinii* pneumonia (PCP). As with non-pregnant women, the risks of developing opportunistic infections increase when CD4+ cell counts fall below 200. Therefore, every effort to prevent infections during pregnancy should be made. *For more about the prevention of opportunistic infections, see page 10.*

Finally, HIV does not appear to affect the development of the unborn child. In fact, the main danger that HIV poses during pregnancy is the risk of infecting the baby. That risk can be greatly reduced by including a variety of HIV transmission risk-reduction strategies into your pregnancy.



Pregnancy and HIV

Some expectant mothers receive prenatal care and HIV primary care from different doctors. Open lines of communication among everyone is important and will, hopefully, help ease the stress of coordinating complex healthcare decisions. *For more information about how to talk to your doctor, read Project Inform's Building a Cooperative Doctor/Patient Relationship available through the National HIV/AIDS Treatment Hotline at 1-800-822-7422.*

Finally, some women note that healthcare providers may not be aware of recent advances in preventing mother-to-child HIV transmission. Others may be judgmental and may even discourage continuing the pregnancy. Some rigidly tell all HIV-positive women never to get pregnant. Such advice is based on ignorance, not science or medicine. If you find yourself in this situation, know that you're doing nothing wrong by your interest in having a child. Seek support from another, more informed resource. This may require seeing another doctor (if that's possible for you) and/or getting support services such as those listed in the *Resource Guide* on page 16. Never forget that you deserve to be treated with dignity and respect!



What Should My Prenatal Care Include?

An initial evaluation will be performed. Depending on the doctor, this exam may vary. However, in addition to standard prenatal exams and required blood tests, it should include viral load and CD4+ cell count tests to assess HIV levels at the beginning of pregnancy. Also, if the mother

is on anti-HIV drugs at the time, the overall trends in her viral load and CD4+ cell counts over the past year should be reviewed to assess the effectiveness of therapy.

During pregnancy there's a normal drop in CD4+ cell count that usually rebounds after birth to pre-pregnancy levels. This is normal and is unrelated to HIV. However, this drop may affect a mother's risk for opportunistic infections (OIs) if her CD4+ cell count drops below 200. If a woman is at risk for OIs, she should be treated during pregnancy with preventive medicines. If it's possible and in the best interest of the woman, preventive OI treatments should start after the first trimester to decrease any danger of medications to the developing baby. *For more information on OIs, see page 9.*



Prenatal Care

Prenatal care is the health care women receive during pregnancy, prior to the baby's birth. It includes education and counseling on managing pregnancy and developing an individual plan of care. For positive women, good prenatal care should consider the HIV issues of both mother and baby. Prenatal care also typically includes recommendations for changes in nutrition, exercise and lifestyle.

Good prenatal care, particularly when started in the first three months of pregnancy, increases the likelihood that a woman will experience a healthier pregnancy and deliver a healthy, HIV-uninfected baby. This is the time when all the baby's major organs are formed. Early prenatal care helps protect a baby from harm during this critical time. For that reason, it's important to see a doctor or visit a clinic as soon as you suspect you're pregnant.

When Should I Begin Receiving Prenatal Care?

If you're thinking about having a baby, it's best to see a knowledgeable doctor even before you become pregnant. Mothers and babies benefit from a well planned pregnancy. Women can improve their nutrition, start taking vitamins early on, and include other health-improving steps (such as quitting smoking and drinking alcohol or getting into drug rehab). These kinds of changes can later benefit the developing child while also improving the health of the mother. Medication changes may be made for women trying to get pregnant because some are considered dangerous during pregnancy.

As soon as you find out you're pregnant, visit a doctor, healthcare provider or clinic. It's important that the clinic staff is familiar with the treatment of HIV-positive pregnant women. Generally, the doctors that women see during pregnancy are obstetricians or family doctors who provide prenatal care and deliver babies. In some areas, women may see nurse midwives. Also, very specialized doctors called perinatologists take care of women who have problems during pregnancy.



Pregnancy and HIV

Other tests performed during prenatal care include those for sexually transmitted diseases, hepatitis B and C, anemia and tuberculosis. A thorough pelvic exam, including a Pap smear, will also be performed. Other routine tests include blood and urine tests and blood pressure and weight monitoring. After the first visit, prenatal appointments usually continue monthly until the beginning of the eighth month. At eight months, a visit every two weeks is usual; and at month nine, visits become weekly.



Prenatal care is not all about tests. Other aspects include nutrition, exercise and lifestyle counseling. Generally, these aspects of prenatal care are the same for all women, regardless of HIV status. A careful assessment

of a mother's nutritional needs will be done to ensure that she eats healthy foods, takes vitamins, and gets enough calories each day. Pregnancy increases the need for calories and protein. Folic acid, iron, calcium and fluids are all important to the baby's development and appropriate levels of each should be included in the mother's diet.

Body and weight changes do occur, and it's important the woman gains enough weight to provide for herself and her baby. While the average weight gain is 25 to 30 pounds, a woman's own build and metabolism determines her own gain.

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 monitor themselves carefully and not overextend themselves. At least eight hours of sleep a night is recommended, and many women will find they require even more.

Are There Prenatal Procedures I Should Avoid?

HIV-positive women should avoid some aspects of typical prenatal care. Most doctors agree that invasive tests and procedures which can cause harm to the developing baby should be avoided whenever possible. For example, amniocentesis, used to test for genetic defects in the baby, is done with a needle that passes through the mother's abdomen

and into the uterus. If these tests are necessary to completely rule out genetic problems that might complicate the pregnancy, they may be performed but at the cost of possible increased risk of HIV transmission.

Prenatal Procedures to Avoid If Not Medically Necessary

- Amniocentesis.
- Chorionic villus sampling (CVs).
- Fetal scalp sampling.
- Cordocentesis.
- Internal fetal and labor monitoring (external fetal monitoring, such as ultrasound, is safe).
- Percutaneous umbilical cord sampling (PUCS).

If invasive tests are necessary, the mother's viral load will be tested. She may be given anti-HIV therapy before the procedure to help decrease the risk of HIV exposure and transmission to her baby. Vaccinations and other treatments that could potentially increase the level of HIV in the blood should also be avoided.

Other Things to Avoid

In addition to avoiding drugs and alcohol, pregnant women should not eat uncooked or undercooked meat. Such meat can cause a number of diseases as well as toxoplasmosis, a serious infection often faced by people with advanced HIV disease. Cat feces can also cause this infection, so pregnant women should avoid contact with cat litter boxes, especially if the cat ever goes outdoors. *For more information on toxoplasmosis and the prevention of other infections, see page 10.*

Because body temperature should not run high during pregnancy, women should avoid hot tubs, saunas or exposure to illnesses that can cause fevers. Also, the body should never become weak or overheated due to exercise. While you exercise, make sure you can speak comfortably.

Doctors urge heavy caffeine drinkers to cut back during pregnancy. This includes coffee and tea as well as soft drinks and herbal preparations that contain caffeine. Finally, all medications, even over-the-counter drugs, should be monitored for safety during pregnancy.



Pregnancy and HIV

Domestic Violence During Pregnancy

About one quarter of women seeking prenatal care report having been abused by their partners. Some studies estimate the prevalence of abuse during pregnancy to be nearly 20%. Specialists estimate that the rate of abuse among pregnant HIV-positive women may be even higher, particularly among young women.

Abused women suffer greatly, as do their babies. They are at increased risk for poor weight gain, infection, bleeding, anemia and substance abuse during pregnancy compared to women who are not abused. Many abused women do not access prenatal care, and those who do more likely seek it in the third trimester, after complications may have already arisen. Babies born to abused women are more likely to be low birth weight and premature. They are also more likely to be abused as children.

No woman deserves to be hurt. While not every woman can leave her abuser immediately, every woman can take safety measures. Talking with somebody you trust—a friend or a health care provider—can be an important first step. Preparing an “emergency kit” in case you have to leave suddenly is important. This should include medications, money, important papers and an extra set of clothes. Most importantly, remember that help is available (see the Resource Guide on page 16).

Just Found Out You’re Positive and Pregnant?

Testing positive for HIV while pregnant can be overwhelming. Not only do you have to think about your own HIV and general health, but you’ve also got to think about the health of your child. This can feel paralyzing, particularly when there are only a few months until the baby is born.

Many decisions you’ll need to make regarding how to best proceed with your pregnancy (including decisions around anti-HIV therapy) depend on how long you’ve been pregnant. Therefore, women diagnosed with HIV when they’re pregnant need a thorough examination and prenatal care as soon as possible.

Take a moment, if you can, to reflect about where you go for support, and choose your support carefully. Even though it’s unfair and irrational, some people may withdraw from you after you tell them you’re HIV-positive. Others may pressure you to terminate your pregnancy or even pressure you to have the child. While you do need to make a decision, you don’t have to make that decision hastily. Take time to determine what that decision is and find the support you need to talk it through and make it happen.

Remember, there is no one right decision for everyone, only the decision that’s right for you.

What Will Other People Think?

If you’re thinking about getting pregnant or are already pregnant, it’s likely that you may confront people who think that what you’re doing is too risky, unfair or simply wrong. These concerns might even be raised by friends or family members. Remember, they are exposed to misinformation through media and people they know. From time to time, you may even question these things yourself. Yet, the choice of whether or not to have a child is a very personal one, and this does not change when you have HIV.

While there’s no absolute way of preventing mother-to-child transmission, plenty of information exists these days to help you minimize the risk. It’s not unusual that women living with HIV are sometimes even more knowledgeable about these things than their own doctors. With the right information and good access to care, the risk can be very low.





Pregnancy and HIV



Anti-HIV Therapy During Pregnancy

At this point, no therapy or approach to pregnancy management eliminates all risk of vertical transmission, nor is there a way to diagnose HIV infection in a baby before s/he is born.

For more information on infant HIV diagnosis, see page 14. Further, the true long-term risk of child health problems associated with using medications during pregnancy remains unknown.

This issue simply hasn't been studied long enough to give clear and reliable answers.

In light of this, developing an anti-HIV therapy strategy that considers the needs of both mother and developing baby can be challenging. However, forming such a strategy is possible with careful consideration of the mother's HIV status, anti-HIV drug history and known and unknown risks and benefits of therapy during pregnancy.

Guidelines for using anti-HIV therapy in pregnant women are generally the same guidelines for "non-pregnant" adults, which includes the use of anti-HIV drug combinations (typically three drugs). The only exception is that certain drugs pose special dangers to either the mother or developing baby. Unfortunately, experience with most anti-HIV drugs during pregnancy is limited. Determining the precise dangers they may pose, particularly to the baby, can be difficult.

AZT (zidovudine, Retrovir) is the most commonly used—and only approved—therapy for preventing vertical HIV transmission. The standard AZT course to prevent transmission during pregnancy involves a three-part treatment scheme. First, the drug is given after the first trimester and through the rest of the pregnancy. Second, it's given to the mother intravenously (in a vein) during labor. Lastly, liquid AZT is given to the newborn child for his/her first six weeks of life.

A study using this regimen showed a decrease in mother-to-child HIV transmission from 25.0% to 8.3%. Thus far, children whose mothers followed this regimen show no significant health differences compared to those who didn't receive AZT, except that those who received AZT were less likely to be HIV-infected.

Ongoing research continues to evaluate the benefits of using AZT and drugs such as nevirapine (Viramune) in different ways. While the goal of these studies is primarily to make prevention plans more accessible and affordable in developing nations, they also provide more options for women in developed nations, particularly without prior use of therapy.

Results of these studies are encouraging. For example, two studies indicate that shortened courses of AZT also result in a significant reduction in transmission. One showed that one dose of AZT given either to the mother during labor or to the newborn within 48 hours after birth cut the rate of transmission nearly the same rate as the three-part regimen. A second study showed that AZT given to the mother beginning at 36 weeks of pregnancy, and then orally every three hours during labor, cut transmission rates in half.

These results suggest that shorter courses of AZT may be as effective as the longer, standard course of treatment previously described. They also suggest that treatment of infants in their first days of life may be particularly important in decreasing transmission risk.

Results from another study suggest that giving a single dose of nevirapine to both mother and newborn infant reduces vertical transmission rates by nearly 50%. More research is necessary to verify these results and determine the long-term effects on the mother and baby.



Combination Therapy

While AZT remains the only *proven* regimen for preventing vertical transmission, AZT as a single therapy has long been shown to be less effective than combination therapy for treating HIV disease. Thus, pregnant women are now encouraged to con-

sider more powerful anti-HIV regimens that best benefit their own health, while refraining from certain drug use which may harm the developing baby. It is also recommended that regimens used in pregnancy include AZT, in addition to any other drugs.



Pregnancy and HIV

Starting or Continuing Therapy During Pregnancy

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 primary reasons for waiting until this time. First, “morning sickness” (nausea common in the first trimester) may make it difficult to keep medications down and can make adherence to medication schedules especially difficult. Waiting until the second trimester, when morning sickness usually subsides, may ease the difficulty of taking medications.

Second, the effects of anti-HIV drugs on the baby during the first trimester remain unknown and of concern. The baby completes the development of its organs at twelve weeks after the last menstrual period. So, many women and healthcare providers 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 not be denied therapy.

Finally, for women who learn they’re HIV-positive late in pregnancy (after 36 weeks), starting therapy later in the course of pregnancy or even during labor and delivery has benefit in preventing vertical transmission compared to what is observed when no therapy is used.

Things may be somewhat more complicated for pregnant women already taking anti-HIV therapy. Stopping therapy during the first trimester to allow for organ development can cause the mother’s viral load to rebound, which may (or may not) lead to increased transmission risk. On the other hand, continuing the regimen throughout the first trimester may negatively effect the baby’s development.

Unless clear data suggest that a risk to the baby’s development is posed, most doctors recommend that women who take therapy continue stable anti-HIV therapy during the first trimester of pregnancy. However, if a woman discontinues therapy, all drugs should be stopped at the same time. Similarly, if the mother restarts therapy during pregnancy, all drugs should be restarted at the same time. An example of when this approach might be used is if a woman cannot “stomach” the drugs during the first trimester because of morning sickness and chooses to stop until the second trimester.

If a woman chooses not to go on anti-HIV therapy during pregnancy, she should continue prenatal care and have CD4+ cell counts and viral load tests to closely monitor the need for therapy.

A few studies report complications to the developing baby possibly due to the mother’s use of combination anti-HIV therapy during pregnancy. Such combinations have included AZT, 3TC, and indinavir (Crixivan). Such problems include prematurity, bleeding in the brain and death associated with a rare brain disorder. While it’s difficult to attribute these complications to anti-HIV therapy, researchers are investigating their potential association. In the meantime, remember that these complications are very rare compared to current indications of the safety and effectiveness of these drugs in other pregnant women.

Moreover, it would be incorrect to assume that these complications are associated with any one particular drug regimen, such as AZT, 3TC and indinavir. Early studies have reported problems in people using this combination, probably because this was by far the most common combination therapy used in 1996 and 1997. Thus, it would be normal to see a higher number of complications reported from people on this particular combination, simply because there were many more people using this regimen.

Overall, except for efavirenz (Sustiva), no patterns of birth defects have been identified due to specific anti-HIV drugs. In animal studies, efavirenz caused serious brain damage. Based on these studies, it is strongly recommended that efavirenz not be used during pregnancy. Even this data, however, doesn’t prove that efavirenz will be a problem in pregnant women. We only know it’s a problem for pregnant mice, but it still warrants caution.

Serious elevations in a pregnant woman’s bilirubin (one measure of liver health) can cause harm to a developing child. Increases in bilirubin levels have been associated with the use of protease inhibitors, a class of powerful anti-HIV therapies. In general, the increases are not serious, but levels should be monitored and therapies changed if bilirubin rises to levels that might cause harm to the child. In particular, indinavir is most associated with increased bilirubin levels. If you take indinavir while pregnant, it’s important your doctor monitor your bilirubin levels with care.

In Summary

In the absence of absolute guarantees regarding which anti-HIV therapies are the safest and most effective, the decision to use therapy and the choice of drugs should be individualized according to a woman’s needs. In the end, the ultimate decision about therapy is the mother’s.



Pregnancy and HIV



One Pill at a Time

Staying on a treatment regimen poses difficulty under the best of circumstances. New triple combinations for HIV disease typically require a person take a number of pills per day, some with specific timing and dietary needs. When using preventive or maintenance doses of drugs for opportunistic infections, the total daily pill count can increase dramatically. Keeping track of one's medication can become a major activity.

The ability to adhere to the schedules and demands of anti-HIV regimens during pregnancy is important to both the mother and her baby. If these treatments are used improperly (e.g., repeatedly skipping doses, taking lowered than prescribed dosages, or not taking at scheduled intervals), the risk of transmission may increase. Moreover, drug resistance may develop and the potential benefits of therapy can be lost to both mother and child. Resistance to one therapy may also result in decreased effectiveness of other therapies (called cross-resistance). These resistant strains of HIV can be transmitted from mother to child. *For more information on transmission of drug resistant HIV, see page 9.*

Drug Interaction Alert

Make sure you tell your doctor about **all** the drugs you take, be they anti-HIV drugs, opportunistic infection drugs or street drugs. The combination of certain drugs may have dangerous interactions, for you and your developing baby. You can also call Project Inform's National HIV/AIDS Treatment Hotline and ask for the *Drug Interactions Fact Sheet*.



Below are a few strategies from Project Inform's *Adherence Discussion Paper*. These may not work for everyone, but they may provide some ideas that can be adopted into your own treatment plan.

- ✓ Blend your treatment plan into your daily routines. Most people find it easier to fit their medications into their lives, rather than scheduling their lives around their medications. Use a daily activity, one that you do every day without fail, to prompt you to take medications.
- ✓ Count out your medications in daily doses for a week at a time. Use a pill box or a nail organizer from a hardware store to hold each dose. Setting up a weekly pill box can become a routine weekend task. Medications can also be divided daily by dose and put into separate containers (some people use film canisters) marked with dosage times. Some people put each canister near the place they will take a dose. For example, put the morning dose by the coffee pot and evening dose by the television set.
- ✓ Keep a checklist for doses taken with a space to note how you're feeling.
- ✓ Plan ahead for privacy if you need or prefer to be discreet about the fact that you take medication. If you're unable to store or take your medication openly, find an unsuspecting place to store your pills (such as a tampon box in the top of a bathroom closet). Some other examples might be adjusting your lunch or break schedule to ensure privacy or keeping water in your bedroom at all times.
- ✓ Keep a diary and include whatever is important to you: when you took treatment, reason for missed dose, how you feel, etc. Keeping a record serves as a reminder of how well, or poorly, you stay on your plan.
- ✓ Set up a support network for your emotional needs. It's hard to take treatment and also deal with daily stress, whether it be taking care of children, working or dealing with illness.
- ✓ Use your support network to remind you of your medication requirements.



Pregnancy and HIV

Vertical Transmission of Drug-Resistant HIV

There have been several cases of the vertical transmission of drug-resistant HIV, including multi-drug resistant HIV. Drug resistance occurs when HIV changes in a way that anti-HIV drugs are no longer effective in inhibiting viral replication.

The cases of vertically transmitted drug-resistant HIV have generally occurred in the following settings: detectable viral load or high viral load during pregnancy, despite the use of anti-HIV therapies. Many cases occurred among women who have had several unplanned therapy interruptions during pregnancy.

While there's still a lot to learn about drug-resistant virus in infants, the prognosis for babies born with drug-resistant HIV is poor. This may be especially true when developing future treatment options for HIV-positive babies already resistant to one or more classes of anti-HIV drugs. Given this concern, some doctors suggest that resistance tests may be useful in helping women develop effective anti-HIV therapy regimens.

Resistance tests have become more widely available with several laboratories offering a variety of these tests. Although laboratories offer these tests, some insurance companies, Medicare and other sources for reimbursement may not cover them. These tests can be very expensive (\$300 - \$1,000 per test). *For more information on drug resistance testing, call Project Inform's National HIV/AIDS Treatment Hotline.*

Managing Morning Sickness

Nausea or *morning sickness* during pregnancy is normal, and usually poses a problem only during the first trimester. However, women living with HIV may experience particular difficulty with nausea. The ability to control it and keep medications "down" is important for two reasons. First, it helps maintain adequate drug levels in your body throughout the day. Second, it helps maintain the nutritional benefits from food. Be assured, however, that when nausea and vomiting occur in the first trimester, it is normal. If nausea persists into the second trimester (weeks 13–26), or if you cannot hold food down at all or lose weight, you should go to the 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 or graham 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.

OI Prevention and Treatment

Treatment and prevention of most opportunistic infections during pregnancy should be similar to those guidelines for non-pregnant women. Prevention for *Pneumocystis carinii* pneumonia (PCP) and *Mycobacterium avium* complex (MAC) is recommended for pregnant women when it's medically indicated. Prevention for tuberculosis (TB) is recommended during pregnancy for HIV-infected women who have either a positive TB skin test or a history of exposure to active TB, after active TB has been excluded.

Preventive measures for certain infections are best avoided during pregnancy because of the potential drug toxicity to the developing baby. These include therapies to prevent candidiasis and other fungal infections, as in the *azole* family [fluconazole (Diflucan), itraconazole (Sporanox) and ketoconazole (Nizoral)]. Prevention against oral (thrush), esophageal, or vaginal candidiasis (yeast infections) with oral *azoles* should not be started during pregnancy. *Azoles* should be discontinued in women who become pregnant.

Finally, vaccines for Pneumococcal, hepatitis B and the flu appear safe for pregnant women and should be offered when appropriate. Live virus vaccines such as measles, mumps and rubella should be avoided during pregnancy.

Consult the *OI Prevention and Treatment During Pregnancy Chart* on page 9 for more information on common opportunistic infections.



Pregnancy and HIV

OI Prevention and Treatment During Pregnancy

Cytomegalovirus (CMV)

A viral infection that, left untreated, can cause diarrhea, blindness and inflammation of the brain.

Indications/Risks

- Positive CMV antibody test for exposure.
- CD4+ cell count below 50.

Treatment

- Individualized.

Additional Notes

- Ganciclovir is not recommended during pregnancy and should be discontinued for women who become pregnant.

Pneumocystis carinii pneumonia (PCP)

An infection that causes fever, cough, difficulty breathing, weight loss, night sweats and fatigue.

Indications/Risks

- CD4+ cell counts below 200.
- Prolonged, unexplained fever (100°F and above for greater than two weeks).
- History of oral candidiasis (thrush).
- History of PCP.

Treatment

- TMP-SMX (one double-strength tablet daily).
- Dapsone (100mg/daily) is an alternative.

Additional Notes

- May delay till second trimester.

Herpes

A viral infection that can cause painful sores and lesions on the mouth, labia (vaginal lips) and/or anus.

Indications/Risks

- History of herpes outbreaks.
- Risk for outbreak increases with immune suppression.

Treatment

- Acyclovir (usually 200mg five times a day).

Additional Notes

- Use for prevention of recurrences during pregnancy is still under investigation.
- Outbreaks during labor may necessitate C-section.

Toxoplasmosis

An parasitic infection that primarily infects the brain resulting in confusion and delusional behavior.

Indications/Risks

- Positive toxoplasma antibody test.

Treatment

TMP-SMX (one double-strength tablet daily).

Additional Notes

- Avoid raw or undercooked meats and avoid contact with cats.
- Other preventative drugs are best avoided until after delivery, unless previously infected.

Mycobacterium avium complex (MAC)

An infection that causes persistent fever, night sweats, fatigue, pain and weakness. May be organ specific.

Indications/Risks

- Risk increases when CD4+ cell counts are below 75.

Treatment

- Azithromycin (1,200mg once weekly).

Additional Notes

- May delay till second trimester or after delivery in women with no prior history or known risk.
- Clarithromycin should be avoided in pregnancy.

Tuberculosis (TB)

An infection that primarily infects the lungs and can cause cough, weight loss and fatigue.

Indications/Risks

- Positive tuberculin skin test or history of exposure to active TB.

Treatment

- INH daily or twice weekly.
- Preventive therapy with INH should be accompanied by pyridoxine to reduce the risk of toxicity to the fetus.

Additional Notes

- May delay until second trimester.
- Treatment for active TB should be developed with OB/GYN and HIV care physicians.
- Pyrazinamide should generally be avoided.



Pregnancy and HIV



Making a Decision About Delivery

Certain routine pregnancy tests and procedures may increase the risk of vertical transmission and should be avoided if possible. Examples include amniocentesis or deliveries assisted by forceps. *For a complete list of tests and procedures to be avoided, please see page 4.*

Another consideration is length of time the baby is exposed to the mother's HIV-containing membranes, including the "broken" water bag, or amniotic sac. Induced rupturing of the water bag should be avoided, as should prolonged exposure to the ruptured membranes, generally considered greater than four hours.

Route of Delivery

C-section vs. Vaginal Delivery

There's a great deal of debate regarding the safest route of delivery of the baby. It centers around the risks and benefits of cesarean-section (C-section) versus natural, vaginal delivery. C-section includes cutting through the mother's stomach muscles and uterus, separating these folds and then easing the baby out. Then the woman's uterus and stomach muscles are stitched up.

In both settings, contact with some amount of maternal blood is unavoidable. To further reduce a baby's contact with the mother's blood, experimentation with *bloodless* C-section continues (see box at right). To date, a couple of studies have compared the risks and benefits of the two routes of delivery. Unfortunately, the results of these studies are often conflicting.

In the setting of HIV, C-sections are increasingly being performed before the onset of labor, a procedure called *elective C-section*. A recent study reports that elective C-section performed before the mother's membranes rupture and labor begins substantially reduces the risk of vertical transmission. This is independent of the effects of anti-HIV treatment. Vertical transmission rates were further reduced when elective C-section was performed in addition to the mother's and baby's use of anti-HIV therapy.

This suggests that elective C-section lowered transmission rates by protecting the baby from direct contact with the mother's HIV-containing genital tract secretions and blood.

While the benefits of elective C-section may sound appealing, there are also some clear drawbacks. Most significantly, C-sections—even elective ones—are not without potentially serious risk to the mother and baby, including maternal hemorrhage (uncontrolled bleeding), infection and other complications. Indeed, studies show that women choosing elective C-sections show significantly higher rates of maternal complications than women electing natural or assisted vaginal delivery. Also, mothers with advanced HIV disease are at highest risk of transmitting HIV to their babies. Such major surgery could further compromise the already tenuous health of these women. In fact, any significant form of surgery presents a heavy burden for HIV-positive people and should be undertaken only if truly necessary.

At this point, there are no clear answers to the question of what type of delivery is best for both mother and baby. Rather, the decision of whether it's best to deliver vaginally or by elective C-section remains a matter of medical opinion and personal choice. With proper precautions, natural vaginal delivery remains a viable choice for pregnant women living with HIV all over the world.

Bloodless C-Section

In addition to undergoing elective C-section, some women choose to undergo a procedure that has been coined "bloodless C-section" or "bloodless delivery." It involves an elective C-section (described above) 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 sack is opened and the baby is removed.

The advantages of this procedure in terms of HIV transmission prevention and its risks to the mother have not been fully explored. The procedure, which is expensive (around \$8,000), is quite drastic and is clearly not for everyone.



Pregnancy and HIV

Are C-sections Always Necessary?

In the past, C-sections were considered life-saving operations performed for women with serious problems during labor. However, in the last several decades, a dramatic rise has occurred in the number of C-sections performed in both HIV-positive and -negative women. In many instances, the C-section was pre-planned and *elective*, as opposed to an emergency response to a complication of pregnancy. In 1996, over one in five children born in this country were born surgically. This is the highest rate of C-sections in the world.

Many have long suspected these operations are too often performed for the convenience of the doctor and fear of malpractice lawsuits, not for the health of mother or baby. In many ways, they have been right.

As major operations, C-sections—including elective ones—are not without risk. In healthy, HIV-negative women, C-sections pose a two to four times greater risk of maternal death than natural, vaginal deliveries. Women who have the operations show much higher rates of post-operative infections. In immune compromised women, these infections could be particularly dangerous. Many women also feel emotional and psychological pain after C-sections.

Delivering your baby is a personal and emotional experience, and how you deliver your baby is a choice. You may choose to undergo elective C-section based on the latest reports that they may lower risk of vertical transmission. You may also choose to deliver your baby naturally. Either choice is a good choice, as long as it's your own.

Emergency C-sections, as a consequence of complications during labor, have not been associated with decreased HIV transmission risk. In this setting, the complications requiring a C-section are thought to increase HIV transmission risks.



Making a Decision About Breast-feeding

HIV is present in breast milk. Researchers estimate a 29% HIV transmission rate from HIV-positive mothers who consistently breast-feed their children. Women living with HIV with safe alternatives to breast milk (as in the United States and Europe) are urged to avoid breast-feeding to decrease the risk of vertical transmission.

For parents who don't want to use bottled non-human milk, human milk banks may be an option. These banks screen donors for HIV and heat treat samples, which preserves the milk's nutritional benefits.

Project Inform Materials Available for You

Project Inform provides many other Fact Sheets and Discussion Papers that help explain the basics of HIV disease, including the *GYN Conditions in Women Living with HIV Discussion Paper, Day One* and *Anti-HIV Therapy*

Strategies. These materials—including the treatment journal, *PI Perspective*—are available free of charge to all those who need them. For more treatment information, contact Project Inform's toll-free National HIV/AIDS Treatment Hotline (1-800-822-7422) or visit our website at www.projectinform.org.





Pregnancy and HIV

Additional Factors Affecting Transmission

Mother-to-child HIV transmission can occur at three stages: before birth, during birth (labor or delivery) and after birth through breast-feeding. Many researchers believe that transmission most commonly occurs around the time of birth, as it does with other infections, like hepatitis B. Evidence suggests, however, that HIV can be transmitted across the placenta (the organ that connects the fetus by the umbilical cord to the uterine wall) within the first 15 weeks of development. Thus, it's presumed that infection can also occur while the developing baby is in the mother's womb (in utero).

No definite predictors of HIV transmission exist, only factors that influence whether or not transmission occurs. However, some factors absolutely do not predict transmission. These include the HIV status of other children, how the woman acquired her own HIV infection, or whether or not her partner is HIV-positive.

Factors that influence transmission include the overall health of the mother, the mother's use of street drugs during pregnancy, and access and use of prenatal care. As discussed previously, the use of anti-HIV therapy has been shown to influence transmission rates, as have the way the pregnancy and birthing process are handled. And again, HIV can be transmitted through breast milk and is thus discouraged.

The mother's health status may be one of the most important factors influencing the risk of mother-to-child HIV transmission. Some studies show that transmission more likely occurs in women with more advanced HIV disease, high

viral loads and/or lower CD4+ cell counts (especially below 200). However, no exact threshold accurately predicts whether or not transmission will occur. Indeed, women in late stage HIV disease with CD4+ cell counts below 200 have had healthy, HIV-uninfected babies.

Regular viral load and CD4+ cell count tests should be used to respond to your own HIV treatment needs. Being responsive to your own needs will, in due course, benefit your unborn baby as well.

Even if a woman chooses to not use anti-HIV therapy during pregnancy, it's important to perform viral load tests regularly. There's still a lot we don't know about the way HIV replicates, or reproduces, during pregnancy. If viral load fluctuates or increases from test to test, it may be wise to reconsider anti-HIV therapy. Only regular viral load testing provides this information.

CD4+ cell count results should also guide treatment and care decision-making. When CD4+ cell counts fall below 200, the risk for certain opportunistic infections increases. Regular CD4+ cell count tests can help determine if there's a need for preventive medication against opportunistic infections during pregnancy. *For more on preventing and treating OIs during pregnancy, see page 9.*

Co-Infections

Many women with HIV also live with other infections, such as hepatitis C, human papilloma virus or herpes. Infection with these and other viruses may increase the risk of vertical HIV transmission. In some studies, women co-infected with hepatitis C are twice as likely to vertically transmit HIV. Knowing if you have other infections can be important in guiding treatment decisions during pregnancy.

Genital herpes is a very common infection, affecting about 75% of HIV-positive women. Pregnant women who are co-infected with genital herpes are more likely than HIV-negative women to have a herpes outbreak in labor. The genital sores associated with a herpes outbreak shed high levels of HIV, even when viral load is below the limit of detection. An infant of an HIV-positive mother with recurrent genital herpes faces the risk of exposure to herpes and an increased risk of exposure to HIV. Preventive acyclovir (Zovirax), an anti-herpes drug that appears safe during pregnancy, is very effective at preventing a recurrent herpes outbreak during labor.

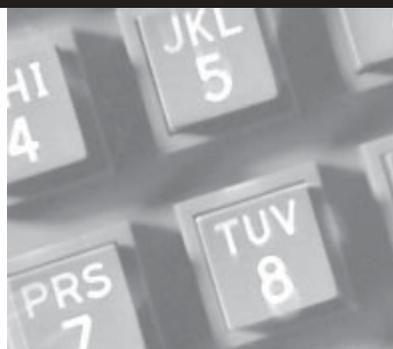
It's easy to contact Project Inform!



1-800-822-7422

Project Inform's toll-free
National HIV/AIDS
Treatment Hotline is
available six days a week:

M - F, 9AM - 5PM
Saturdays, 10AM - 4PM





Pregnancy and HIV

Other sexually transmitted diseases, such as syphilis and candidiasis (vaginal and oral), are also associated with a higher risk of vertical HIV transmission. A recent study demonstrated a high rate of bacterial vaginosis among HIV-positive pregnant women. It suggests that abnormalities due to bacterial vaginosis may place pregnant women at an increased risk for pre-term labor, an outcome associated with increased risk of vertical HIV transmission. Thus, it's important for the expectant mother to receive treatment for these infections to reduce the risk.

Other Factors:

Street Drugs, Cigarettes and Alcohol

Some women may have drug or alcohol habits that could be difficult to stop even if they find out they're pregnant. While this is understandable, the adverse health effects that the baby will experience from the mother's habits are enormous.

Organizations specialize in helping women kick addictions, and pregnancy is an especially important time to consider doing this. Any doctor or clinic providing prenatal care can refer people to these resources.

Alcohol should be avoided, especially early in pregnancy, because it can cause fetal alcohol syndrome. The most severe symptom of this disease is mental retardation. Cigarettes cause low birth weight and premature births, as well as miscarriages. This is because nicotine causes blood vessels to constrict, which means that less oxygen and nourishment can reach the baby.

Street drugs, like marijuana, cocaine and crack, are also very harmful for the developing fetus. They act the same way as nicotine does—decreasing the amount of oxygen and food that reaches the baby. They also cause babies to be born with addictions and birth defects and can even cause miscarriages.

Street drugs, particularly injection drug use and crack-cocaine, are also associated with increased vertical HIV transmission rates. The risk of mother-to-child HIV transmission and complications associated with the use of street drugs can be significantly decreased when pregnant women get into early prenatal care and drug abuse programs during pregnancy.

Learning if You're Baby is HIV-Positive or Negative



It's not unusual to want to know right away whether or not your baby is HIV-positive or negative. Still, it often takes at least three months and as long as eighteen months 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 those who are not truly 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, and it takes time for the baby to lose them and develop its own.



WISE Words is the three-times yearly publication of **Project WISE**, Project Inform's program focused on HIV/AIDS treatment information and advocacy for women. Each issue provides women with important tools for making HIV treatment decisions, covering topics such as anti-HIV therapy, prevention and treatment or opportunistic infections,

gynecological health and more! If you would like to be added to the mailing list for **WISE Words**, call Project Inform's toll-free National HIV/AIDS Treatment Hotline at 800-822-7422, or email WISE@projinf.org.



Pregnancy and HIV

Nutrition and Weight Gain Issues

Your and your developing baby's bodies depend on you to provide them with sufficient calories and nutrients to grow and live healthily. Poor nutrition and insufficient weight gain from the mother can increase the risk of a premature or low birth weight baby, increasing the risk of transmitting HIV. Positive women may have trouble gaining weight and may gain less than what is usually recommended during pregnancy (*Prenatal Care*, page 3). Common side effects from anti-HIV medication can make gaining weight difficult or even cause weight loss.

Age

While healthy older and younger women can and do have healthy HIV-uninfected babies, women of certain ages are at increased risk of HIV transmission. Older women are more likely to have a low birth weight baby, thus leading to increased risk of HIV transmission. Young women are likely to have an undeveloped cervical area which may increase cervical shedding of HIV during vaginal delivery. Healthy pregnancies in younger and older women are nonetheless possible.

Commentary

Advances in anti-HIV therapies offer many benefits in maternal and child health, most notably in terms of reducing the rates of vertical HIV transmission. Yet, anti-HIV therapy remains only one part of a prevention strategy and it may or may not make sense for all women. Regardless of a woman's decision around the use of therapy, good prenatal care and addressing surrounding health issues are key to a prevention strategy. Prioritizing the mother's health before, during and after pregnancy is the most important step toward good health for both mother and child.

There is not a 100% effective strategy for preventing mother-to-child transmission of HIV. Even if a woman receives optimal prenatal care, stops using drugs, alcohol and cigarettes, starts an exercise and nutritional program and initiates anti-HIV therapy, there is still a chance—albeit increasingly small—that her baby will be HIV-positive. The risk of transmission can be significantly reduced, but so far, no study has shown a way to eliminate it completely. It's important to remember what factors you have control over and can do something about, and what factors are truly out of your hands.

Often times, preventing HIV transmission from mother-to-child is discussed in the context of women who are learning

of their HIV status at the same time they discover they're pregnant. For these women, it's important to acknowledge how easy it is to become paralyzed by the overwhelming information and the flurry of emotions.

Take a step back and truly take a moment to think about who you turn to and where you go for support. Some people might try to influence decisions about your pregnancy, and that advice may be clouded by their own judgements of "right" and "wrong". This is not an uncommon experience among women living with HIV. Support is out there. You may just have to look a little harder for it.

Finally, anti-HIV medications are very effective in preventing vertical transmission in the United States and Western Europe. However, with the prohibitive price of these drugs, it's unlikely that these regimens will be made widely available to pregnant women in the poorest countries. There's still a great need for safe, inexpensive and effective regimens to prevent vertical transmission in these countries, as well as realistic alternatives to breast-feeding.

CONNECT ONLINE TO
PROJECT INFORM!



Learn more about Project Inform! Just get on the World Wide Web and find us at:

www.projectinform.org

Look for and click on the icon  for *Women's HIV/AIDS Treatment Information*.

Find out what Project Inform is doing with regards to HIV/AIDS treatment information and advocacy for women. Read current and past issues of *WISE Words* and comprehensive treatment articles like *GYN Conditions in Women Living with HIV/AIDS* and *Women and AIDS*.

Please email us your suggestions about how we can improve our services. The email address is WISE@projinf.org.



Pregnancy and HIV

Resource List

Women's Programs/Newsletters/Hotlines

WISE Words: 1-800-822-7422

PI Perspective: 1-800-822-7422

205 13th Street, Suite 2001, San Francisco, CA 94103

WISE Words is the free, three-times yearly publication of Project Inform's program focusing on HIV/AIDS treatment information and advocacy for women, called Project WISE. PI Perspective is published three-times yearly and contains more information of interest to women living with HIV.

Women Alive: 1-800-554-4876

1566 Burnside Avenue, Los Angeles, CA 90019

Women Alive publishes a quarterly newsletter and is active in policy and treatment issues affecting women living with HIV.

WORLD (Women Organized to Respond to Life-threatening Diseases): 510-986-0340

414 Thirteenth Street, 2nd Floor, Oakland, CA 94612

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

HIV/Pregnancy Information

BAPAC (Bay Area Perinatal AIDS Center): 415-206-8919

This San Francisco General Hospital clinic provides comprehensive primary and prenatal care and access to clinical trials for HIV+ pregnant women.

Antiviral Pregnancy Registry: 800-722-9292 x39437

POB 13398, Research Triangle Park, NC 27709-3398

Kept records document whether HIV drugs cause problems in pregnancy.

Positively Aware newsletter: 773-404-8726

Bi-monthly newsletter for people living with HIV. Ask for the "She's Having a Baby" and "HIV & Pregnancy" Issues.

The Women's Initiative for HIV Care & Reduction of Perinatal HIV Transmission (WIN): 301-443-9051

This organization sponsors projects in New Orleans, Dallas, Philadelphia, Ft. Lauderdale, New Jersey, Maryland and Massachusetts.

Domestic Violence

National Domestic Violence Hotline: 1-800-799-SAFE

This 24-hour hotline is staffed by trained counselors ready to provide immediate crisis intervention to those in need. Callers can be connected directly to help in their communities, including emergency services and shelters.

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 Treatment Information Hotlines

National HIV/AIDS Treatment Information Hotline: 1-800-822-7422
International/Local Hotline: 415-558-9051

Project Inform is the nation's leading HIV/AIDS treatment information source.

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.

Research/Clinical Trials Hotlines

Pediatric AIDS Foundation Trials Hotline: 310-395-9051

1211 Colorado Avenue, Santa Monica, CA 90404

The Pediatric AIDS Foundation advocates on behalf of and funds pediatric research in AIDS. This trial hotline gives listings of studies and provides information and referrals for children with HIV/AIDS.

American Foundation for AIDS Research (AmFAR): 1-800-39AMFAR

A non-profit organization dedicated to HIV/AIDS research, prevention, and advocacy.

AIDS Clinical Trial Information Service: 1-800-TRIALS A

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

Special Programs for Children and Families Affected by HIV/AIDS

FCAN (Families and Children's AIDS Network): 312-665-7360

721 North LaSalle Street, #311, Chicago, IL 60610

FCAN works to meet the needs of families and children living with HIV/AIDS through information, referrals, educational forums, coordination of services among providers, and the Network News newsletter.

NPHRC (National Pediatric HIV Resource Center): 1-800-362-0071

15 S. Ninth Street, Newark, NJ 17107

NPHRC provides consultation, training, and a forum for exploring public policy issues about pediatric AIDS. They have developed recommendations on the medical management of HIV-infected children and have a publications list.

Human Milk Banks

Mother's Milk Bank: 408-998-4550

Valley Medical Center, PO Box 5730, San Jose, CA 95150

Memorial Health Care, Regional Milk Bank: 508-793-6005

119 Belmont St., Worcester, MA 01605

Mother's Milk Bank: 303-869-1888

Columbia P/SL Hospital, 1719 E. 19th Avenue, Denver, CO 80218

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. Medical and Medicaid covers the total cost of milk. Some private insurance companies are beginning to cover it as well.