



**THE POSITIVE PREGNANCY GUIDE**  
**A Guide for HIV+**  
**Moms-To-Be**

**TMC**  
TRUMAN MEDICAL CENTERS



# The Positive Pregnancy Guide

A Guide for HIV+ Moms-To-Be

## My Personal Guide to a Healthy Pregnancy

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Name

**H**ope is always available to us. When we feel defeated, we need only to take a deep breath and say, “Yes,” and hope will reappear.

-Monroe Foster

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## **The Positive Pregnancy Guide is a workbook designed to help you learn more about HIV and pregnancy.**

Our goals in providing you with this workbook are:

1. Keep you as healthy as possible during and after your pregnancy and,
2. Help you deliver a healthy baby who does not develop HIV.

*The information in this workbook only addresses specific aspects of care. Please talk with your health care providers if you do not understand something or need more information. They have a lot of information to share!*

*The information provided in this workbook was developed by the staffs of Truman Medical Center's Infectious Diseases and OB-GYN clinics. Additional information regarding pregnancy, childbirth and delivery was obtained from the 4women.gov website used with their permission.*

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# HIV MOM-TO-BE

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# You're Pregnant!!!

*Congratulations!!* How exciting! This is a happy time for you as you begin planning for a new member to join your family. This is also a time to be very involved in your healthcare because you have HIV.

You may have just discovered you have HIV or you may have known your HIV status for many years. You probably have many questions about your health and the health of your unborn baby. You will need to learn not just about pregnancy, but how HIV affects both you and your unborn baby.

The **Positive Pregnancy Guide** will try to answer your questions and provide you with the knowledge you will need to make decisions for your healthcare. Our goal is for you to be as healthy as possible during and after your pregnancy and deliver a healthy baby who is free of HIV.

Use this book as a learning tool and workbook. Write in the margins, circle things you have questions about, document your appointments and lab results and keep track of frequently used numbers!

## Making Sense of HIV and Pregnancy

### What is HIV?

**HIV** is a virus that attacks your body's immune system. It's not like other viruses. Viruses that cause a cold or the flu stay in your body only a short time. When you have HIV it stays in your body because your immune system can never completely kill it.

Eventually it can weaken your body's defenses against disease. Over many years, HIV can cause AIDS (Acquired Immuno Deficiency Syndrome).

If you recently learned that you are HIV+, ask your healthcare provider or case manager to help you make decisions about testing your children.

The past few years have been a rollercoaster of emotions, sickness and discovery. I am one of those people who sees life as an adventure; this is simply another one. All the wise people I know, and the heroes I have read about, are just human beings. We all have our strengths and weaknesses. I have made my mistakes, some of which I've learned from, but I have lived my whole life; I have gotten my hands dirty. I am proud of myself. This short story has been a damned interesting one, and is not over yet.

*-Tony Gonda*

## POSITIVE LIVING

### How does someone get HIV?

HIV is passed from person to person by exchanging body fluids such as semen, vaginal fluids, blood or breast milk. A person can get HIV in one of these ways:

- Unprotected Sex with someone who is infected with HIV (without a condom or other barrier).
- Sharing a needle that has been contaminated with HIV-infected blood.
- Perinatal transmission can occur with a baby who is born to a HIV+ mother. Transmission of HIV can occur in the womb, during birth or through breast milk. There is a one in four chance (25%) that your baby will get HIV if you do not take medications. Medications taken as recommended by your provider during pregnancy greatly reduce these chances.

You **CANNOT** pass HIV through casual contact-hugging, kissing, holding, crying, sweating, touching, sharing food.

### How does HIV affect my immune system?

Your immune system helps keep you from getting sick, and helps you get well when you are sick. It is made up of many cells that have different jobs. Some of these cells are called CD4 cells or T cells.

- HIV uses your CD4 cells to make new copies of itself, destroying the CD4 cell in the process.
- The new viruses then infect other CD4 cells and make more virus. In fact, one virus can make as many as 10 billion copies of itself in one day.
- To fight off HIV, your body makes new CD4 cells to replace those destroyed.
- When there are extremely high numbers of HIV in your blood, more and more CD4 cells die.

- Slowly, the number of CD4 cells in your body goes lower and lower and the amount of HIV gets higher and higher. This makes your immune system weak and unable to fight other infections.

*Even if you do not feel sick, HIV is killing CD4 cells, and weakening your immune system.*

### **What is the difference between HIV and AIDS?**

As we discussed, HIV is a virus that infects and destroys the cells of the immune system. Eventually, HIV infection can worsen to a severe form of immune weakness known as AIDS. There are many ways your doctor can determine if your condition has become what is called AIDS. A CD4 cell count that is below 200 or by having certain infections, called “opportunistic infections” (these infections will be discussed later) are two ways your doctor can make this distinction. There are also many cancers that can occur more commonly when a person has AIDS. Only your medical provider can tell you if you have AIDS.

## **POSITIVE LIVING**

### **How do I fight HIV?**

If you have HIV, you may feel, look, and act just fine. But, once you know that you have HIV, it is very important to take good care of yourself. This is the key to delaying the onset of more serious problems. Always take care of yourself:

- Take your medicines
- Practice good nutrition
- Commit to a healthy lifestyle
- Visit your health care provider regularly

It is also important to keep a positive outlook on life!!! Hope is very important. Everyday there are new drugs and treatments for HIV that may help you.

- Each time you visit your doctor, be sure to ask about new treatments and clinical trials (research studies) in which you might take part.

Being HIV positive opened my eyes to life, which I was so blind to before. I began to enjoy the simple things that people take for granted, like nature, the creatures of the earth, and children, who carry so much love in their hearts. A new life after the hell of drugs and alcohol that I lived before. Life is what you make it, and with my sons love, I'll live forever.



- Try not to worry. Worrying can lead to stress, and stress can weaken your immune system.
- Take steps to reduce stress. Activities that may relieve your stress include breathing exercises, walking, reading, and community activities.
- Ask your health care provider about ways to cope with worry and stress.

Some steps to staying healthy are:

- Keep regular appointments with your doctor (even if you don't feel sick).
- Take your medicine correctly, even if you are feeling better (remember, HIV is killing CD4 cells even when you do not feel sick).
- Get immunizations (shots) to prevent other infections, such as pneumococcal pneumonia or hepatitis B.
- See a dentist every six months to have your teeth and gums examined and cleaned.
- Brush your teeth at least twice a day. Mouth infections are common in people with HIV.
- Wash your hands to prevent infections from occurring. Especially, wash your hands after using the toilet and after being around someone who has a cold or flu. Encourage people around you to wash their hands often to avoid passing on their germs.
- Eat healthy and nutritious foods. This will help keep you strong, keep your energy and weight up, and help your body protect itself.
- Exercise regularly, but moderately, to maintain muscle. Walking daily is a good choice for exercise.

Even if you don't have symptoms, you must continue to do positive things to fight HIV.

Maintain your health and protect your immune system!

- Get enough sleep and rest.
- Stop unhealthy habits. If you smoke, drink alcohol or do drugs....QUIT!!. Smokers have more secretions in their lungs than non-smokers. These secretions make it easier for organisms to grow. Alcohol and drugs such as cocaine, marijuana, and amphetamines are dangerous for a person with HIV. They can further lower your resistance to infections, interfere with your medicines, and cause problems with your nutrition. Please talk to a member of your healthcare team or your case manager about counseling or other options.
- Keep your spirits high. Know what it takes to get you back into high spirits. Write down what makes you feel happy and supported. When your days feel lower, re-read what you wrote on those happier days. You can even ask your Case Manager to be the person you call when you need a pick-me-up!!

- Join a support group. You are not alone in this battle. Talking to someone with your same illness can strengthen your determination to live.

My personal goals to stay healthy, fight HIV and have a health baby:

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### **Kicking Bad Habits!**

To be a healthy mom and to have a healthy family, you need to make sure your health is good. Now is the time to give up smoking, drinking, drugs and unhealthy foods. This will reduce birth defects and keep you and your baby safe.

Smokers have more secretions in their lungs than non-smokers. These secretions make it easier for organisms to grow. Alcohol and drugs such as marijuana, cocaine, PCP and amphetamines are dangerous for a person with HIV. They can further lower your resistance to infections, interfere with your medications and cause problems with your nutrition.

You and your case manager can identify habits that you may want to change. Change is tough on your own, so make sure you have support cheering you on.



### **Can someone help me?**

There are special substance abuse programs in the area that can help you stop. Below are a few questions about substance use:

1. In the month before you found out you were pregnant, were you smoking?
2. In the month before you found out you were pregnant, were you drinking?
3. Have you ever felt bad or guilty about your drinking or drug use?
4. Have you used marijuana since you became pregnant?
5. Have you used any other drug since you became pregnant? (Examples would be crack, cocaine, PCP, methamphetamines, etc.)
6. Since you have been pregnant, have you used drugs or alcohol first thing in the morning to steady your nerves or to get over a hangover?

If you answered yes to any of the questions above, you can always ask for help. Talk to your medical provider, nurse, case manager or social worker for help.

*It is hard to get help or to quit by yourself. It is a process and will take time.*

### **When should I call the clinic?**

It is important to tell a member of your healthcare team when you are feeling sick. Some symptoms you should report include:

- sores or white patches in your mouth
- changes in your eyesight
- shortness of breath
- diarrhea – more than 5 watery stools a day
- weight loss
- trouble swallowing
- headaches or dizziness
- trouble remembering things

In the Stages of Your Pregnancy section, there are more lists of what to watch for in each trimester.

Be sure to write emergency numbers, clinic numbers, and after hours contact information in the Helpful Numbers section of your book.

## POSITIVE LIVING

If I get sick, how long should I wait before I call the clinic? We can't stress enough how important it is to **keep your clinic appointments**. Even though you feel well, certain lab results could indicate that you might be at risk for infections. Your medical team wants to prevent you from getting sick if at all possible. However, there are going to be times you will become ill between clinic visits. Flu and colds are common. Sometimes though, it is hard to tell if a cough and fever are just a cold or a symptom of some other infection.

If you have symptoms that no one else in your household has, such as diarrhea or vomiting, or your symptoms last longer than 2 or 3 days, you should notify your healthcare provider. Tell the nurse or healthcare provider what your symptoms are and how long you have been feeling ill. Your healthcare provider can then decide if you need medical treatment.

### **What should I do if I get sick when the clinic is closed?**

If you become sick after clinic hours or on the weekend you may call the Truman Medical Centers at 816-4040-1000 and ask to speak to the ID provider on call.

If you go to the Emergency Department remember to take your:

- Identification card
- Your medications
- Health information you might have
- Health insurance or Medicaid cards

**Always tell the healthcare staff you are HIV+.**

AIDS brings out the very best and the very worst in people. Some succumb to their fears and some triumph over their illness. I've seen people really come to terms with themselves and find happiness and peace of mind, and I've seen people who have been defeated by it, who have pushed their friends and family away and have died isolated and alienated. You can't deal with this disease alone. You need to reach out to people with love. If you reach out with love, you get back love ten-fold.

*-George DeSipio*

## **Should I tell anyone I have HIV?**

Your HIV status is very personal, and telling other people that you have HIV may be one of the hardest things you will ever have to do. When you first find out you have HIV, you may feel sad, depressed, ashamed, or afraid. Telling other people about your HIV infection may mean that you will get more support and help from others, but it can also lead to problems such as rejection by family, friends or your employer. You should take time and decide who you would like to talk to first about your HIV infection.

Local or state laws require that your healthcare provider report your HIV status to the health department. Otherwise, your HIV infection should be kept confidential, unless you decide to talk about it.

The law states you must tell all your sex partners or people you inject drugs with that you have HIV, or face possible fines or jail time if you do not.

If there is one thing I'm sure of, it's that this disease may change your life, but it doesn't end it. It becomes a part of you, just one part. It doesn't define you, and it definitely doesn't destroy you. Have I learned to live with it? Yes, I have.

*-Jack Rosenberg*

## **POSITIVE LIVING**

### **Who should I tell?**

You must tell the people that you have sex with, share needles with if you inject drugs and your healthcare providers. You should talk to your sex partners about using condoms for safer sex and about the risk of having a baby with HIV. If you inject drugs, you will want to discuss the danger of sharing needles.

### **You may also want to tell:**

- Members of your family
- Your close friends
- Your co-workers
- Neighbors
- Members of your church
- People at school (if you are a student)

Some people with HIV choose not to talk to family or friends about their health and that's okay. It is your choice. Telling important people in your life about your HIV status is called **Disclosure**. Your fears may be real and you may need to think about how you will do it. Before you tell someone about your HIV, ask yourself these questions:

- What is making you nervous about telling them?
- Are you afraid of how they will act?
- Are you afraid of what they will say?
- Will they be able to keep your information confidential?

Remember, if you want to tell someone about your HIV, but are nervous, you can call your Family Case Manager and talk about how you feel. You can get support or practice what you will say.

### **How can I make sure I don't give someone HIV?**

HIV can be transmitted (passed on) to another person by:

- Having vaginal, anal or oral sex without a condom
- Sharing needles or syringes
- Receiving HIV infected blood or blood products
- Pregnancy or childbirth
- Breast milk

You can reduce the risk of giving someone else HIV by:

- Telling every potential sexual partner that you have HIV
- Using condoms every time you have vaginal, anal or oral sex
- Avoid sharing personal care items which might have come in contact with small amounts of your blood, such as toothbrushes or razors
- Using birth control to avoid an accidental pregnancy
- Not sharing needles
- Not donating blood, semen, bone marrow, or other organs
- If your partner dies bit gave GUV talk to you provider about PrEP. This stands for Pre-exposure Prophylaxis. Your partner can be given a prescription for medication



that he/she would take one pill once a day to prevent getting HIV. Studies have shown that this is an effective way to prevent getting HIV when used with condoms.

- Maintaining a undetectable HIV viral load (less than 20 copies) also prevents spreading HIV. Make certain you are taking your HIV medications and following up with your provider at least 4-6 months.

### **What is Safer Sex?**

There is no such thing as “safe sex”. However, you can greatly reduce the risk of giving someone else the HIV virus if you tell them you have HIV and use a condom every time you have vaginal, anal or oral sex. **HIV is also in the “pre-cum,” so you should put the condom on before you begin having sex.**

Other safer sex activities include kissing, hugging, touching, body massage, mutual masturbation, and the use of one’s own sex toys. Having only one sexual partner also reduces the spread of HIV.

Unsafe sexual practices include:

- Vaginal, anal or oral sex without a condom
- Oral-anal contact (rimming)
- Urinating (golden showers) on a partner’s broken skin
- Sharing sex toys
- Inserting hand/fist into partner’s rectum or vagina (fisting)

Drinking alcohol or taking drugs may cause you to “forget” to practice safer sex.

There are options-some are fun and exciting! There are also counselors who specialize in safer sex and planning to reduce the risk of transmission to others. Ask how one can help you!

## TREATING HIV DURING PREGNANCY

There are two goals in treating you during your pregnancy. The first is to prevent **vertical transmission**, which is to prevent passing the HIV infection from you to your unborn baby. The second goal is to treat your HIV with the same medical standards that would be used if you were not pregnant.

*Without treatment the chances of mother-to-child transmission is thought to be about 25% or 1 out of 4 births.*

It appears that the HIV virus may be transmitted during pregnancy, labor and delivery or through breast feeding. Some factors which may influence the risk of infection are the mother's viral load, whether she is receiving **HIV therapy** (taking medicines that fight HIV), the duration of labor and delivery, and the type of delivery (vaginal or C-section).

Some treatment information sounds scientific or is hard to understand. Ask your medical provider or case manager to help explain treatment options to you in an easy to understand way. It is tough information!

***Remember, you don't have to know all of the science, but still ask questions that are important to you.***

### How is vertical transmission prevented?

There is a 3 part regimen of HIV medications that is the most commonly used therapy for preventing vertical transmission. A study completed in the United States using this regimen showed a decrease in the mother-to-child HIV transmission rate from 25% to about 8%.

The 3 parts include:

- 1) The mothers begins taking HIV medications by mouth after the first trimester and through the rest of pregnancy.
- 2) Zidovudine given to the mother by vein (IV) during labor.
- 3) Liquid Zidovudine is given to the newborn for 6 weeks.

Ongoing research continues to evaluate the benefits of using Zidovudine and other drugs in prevention of vertical transmission and to determine long-term effects of these drugs on both you and your baby. Thus, in achieving the second goal, which is to adequately treat you, pregnant HIV+ women are encouraged to take the more potent combination therapies that are considered standard medical care for HIV infection.

### **Should I avoid some medications?**

There are a few exceptions, where certain medicines should be avoided or need special monitoring in pregnancy because of potential harm to the developing baby.

- In animal studies, efavirenz (Sustiva) caused serious damage in developing fetuses. Based on these studies we recommend that efavirenz not be used during pregnancy.
- For pregnant women receiving protease inhibitors, the mother's serum bilirubin should be monitored for increasing levels. This is because protease inhibitors have been known to cause increases in bilirubin and elevations in a pregnant woman's bilirubin can cause harm to a developing child.

### **When should I begin HIV therapy?**

- During the first trimester there is not an urgent medical reason to begin HIV therapy.
- Some recommend waiting to initiate therapy to the 12th or 13th week of pregnancy. This delay avoids starting new drugs (some that may cause nausea and vomiting) during a time when morning sickness is common, a situation that would make adherence with new medications especially difficult. Also, the developing fetus is thought to be most sensitive to **teratogenic** effects (drug induced abnormalities in the developing fetus) during the first trimester.

If you are already taking HIV therapy when you discover you are pregnant, there are not specific recommendations whether you should continue your therapy or stop your therapy until you are past the first trimester. The potential risk of rebounding viral load and increased risk of transmission if you discontinue therapy must be weighed against the poten-

tial risk of drug effects on development of your unborn baby.

If you do discontinue HIV medicines whether related to morning sickness or for the first trimester, all drugs need to be stopped at the same time. Similarly when drugs are to be restarted they must be started at the same time. Ask your doctors what you should do.

If you choose not to go on HIV medicines during pregnancy, you should continue close prenatal care with frequent viral load tests and CD4 counts to monitor for changes that might change the considered risks and need for therapy. Ask your providers what you should do.

After delivering your baby, you and your doctor should discuss your HIV status to decide whether you should continue taking the current HIV therapy.

*Remember your baby needs to be treated with zidovudine (AZT) for 6 weeks following delivery.*



## POSITIVE LIVING

I'm the same person that I was five years ago; I feel exactly the same. But in fact, I'm sick-or at least I have a compromised immune system. And that's very hard to accept. How should I relate to society, and how should society relate to me? Being HIV positive is like living in a world unto itself, like belonging to a clique of sorts. Today I have a new circle of friends, a new education, and a new vocabulary. All of this definitely comes under the heading of things you never wanted to know, but do.

*-Barry Miguel*

### As for anybody taking HIV therapy, pregnant women need to think of these important issues:

- **Drug interactions** – there are many drugs that increase the chances of side effects related to HIV drugs. Many can make the HIV drugs less effective, and the HIV drugs can do the same to other drugs you may take. Be sure to tell your healthcare team about ALL of the drugs you take including things you buy without a prescription, such as herbal products, dietary supplements, vitamins, or botanicals.
- **Adherence** – Everyone on your healthcare team will tell you adherence is the key to successful therapy. Communicate with the healthcare team about what is or is not working for you.
- **Know your numbers** – you can follow your viral load and CD4 counts. These numbers can be indicators of your progress toward your goals. You want your viral load to be undetectable or as low as possible. This will reduce the chances that your baby will become HIV+.



## Questions or thoughts I have today...

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### What about infections or vaccines?

Treatment and prevention of opportunistic infections are also important during pregnancy and should be similar to those that would be used if you were not pregnant. Treatment and prevention of **PCP, MAC, and TB** are recommended for pregnant women when typically medically indicated.

Some vaccines are appropriate for pregnant women, such as for influenza (flu), Pneumococcal (pneumonia), and hepatitis B (if you are at risk for exposure). Other vaccines must be avoided in pregnancy including measles, mumps, rubella, and varicella.

My medications or vaccines:

(Prescription Name)	(Dosage)	(Schedule)
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# Clinical Trials

## **What is an AIDS clinical trial?**

These are special studies that test new medications or treatments. The law states that Ryan White Title IV programs must make clinical trials information available for women like you.

## **What are the benefits to HIV+ women?**

Patients in clinical trials might get access to new treatments before they are available to the public and get expert care, free of charge. Your participation may help other women living with HIV by contributing to medical research.

## **What are the risks an HIV+ woman could face?**

Patients taking research medications may not have any benefits or might face risks. Make sure you know what is expected of you when you participate in a clinical trial.

## **Get your questions answered before participating in clinical trials:**

- Will the clinical trial medications harm my baby?
- What are the treatment side effects?
- Will I have to travel or stay in the hospital?
- Can I quit the clinical trial at any time?
- Are there any other treatment options that will work better for me?

## **How do I find clinical trials on HIV and AIDS?**

1. Ask your doctor, nurse or case manager.
2. Call AIDS Clinical Trials Information Service: 1-800-448-0440
3. Look on the internet for listings and information at:
  - [www.thebody.com](http://www.thebody.com)
  - [www.aidsinfo.nih.gov](http://www.aidsinfo.nih.gov)
  - [www.poz.com](http://www.poz.com)

## **How do babies get HIV?**

The virus that causes AIDS, HIV, can be transmitted from an HIV+ mom to her baby. It is not clear if HIV is passed to the baby during the pregnancy or during delivery. About 25% of babies born to HIV+ moms who are NOT on medicines to fight HIV are at risk of having HIV.

The baby may also be at risk of getting HIV if the delivery takes a long time. The baby may be exposed to more blood and body fluids when this happens. Your OB provider may recommend a C-Section to decrease the risk to your baby. An HIV+ mom may also give her newborn baby HIV by breastfeeding.

HIV+ Moms are advised not to ever breast feed their babies. It is very important that your baby be seen by a doctor to be tested for HIV. Your case manager can help arrange that for you.

To protect my baby from HIV, I need to:

- Make and keep regular appointments with my OB and HIV providers.
- Take anti-HIV medicines as my doctor instructs me. These medicines fight HIV and reduce the risk of giving my baby HIV from 25% to 2%.
- Talk to my doctor about the possibility of having a C-Section.
- DO NOT BREASTFEED MY BABY.
- Talk to my case manager about helping me stick to my medications and getting extra help I need during my pregnancy.
- Ask my doctor or nurse about programs to pair me with a peer counselor who can remind me of my appointments, times to take medications and help me with other challenges I might face.

# STAGES OF YOUR PREGNANCY

## YOUR PREGNANCY

Your pregnancy is a thrilling and unique time that can also be a little scary. Having a baby means so much more than just carrying around some extra weight for the next nine months. That new life growing inside of you will depend on you for everything he or she needs to be healthy and strong, before and after he or she is born. By educating yourself about pregnancy, you can learn what you need to do to promote a healthy pregnancy and ensure that you are doing everything you can to keep you and your baby healthy.

For 9 months, your body and your baby will be going through many different changes.

With each trimester, there are new experiences, tests, and challenges.

Your nutritional needs will change during pregnancy, so be aware of what you are eating and drinking. What you eat will affect your baby. Drinking alcohol, smoking, drugs and many other things can harm the development of your child.

- The first trimester is the most important stage in the baby's development. Most of the baby's important organs are being formed, and the baby will be growing and gaining weight for the rest of your pregnancy.
- During the second trimester you will notice your body changing and growing to accommodate the baby growing inside you. During your ultrasound, you might even discover if your baby is a boy or a girl. You will continue to gain weight and experience new changes as you enter the 3rd trimester.
- In the third trimester, your baby is near birth, there are choices that need to be made as well as preparations for a newborn.

All these changes and decisions might seem overwhelming, but just remember that your body will adapt to the demands of pregnancy. After the birth, your body will begin to re-adjust to the way it was before you became pregnant. But give it time, it took nine months to have a baby and it might take some time and work to get your body back to the way it was before you became pregnant.

While you are pregnant, there are many things you can do to help your pregnancy progress as smoothly and easily as possible. Eat a healthy diet, exercise and visit your healthcare provider (both your OB and HIV provider) on a regular basis. Taking medicines to fight HIV is as important as a healthy diet and exercise. And seeing your healthcare provider regularly assures that the medicines are working like they should to decrease the risk of passing on HIV to your baby.

*Don't be afraid to ask questions, and don't forget that there is help available if you need it.*

## **THE FIRST TRIMESTER**

### ***Congratulations!***

Your journey to motherhood is underway. During the first 3 months of pregnancy, or the first trimester, there are many changes happening to you.

- As your body adjusts to the growing baby, you may experience nausea, fatigue, backaches, mood swings, and stress. Just remember that these things are normal during pregnancy. Most of these discomforts will go away as your pregnancy progresses, so try not to worry about them.
- Just as each woman is different, so is each pregnancy.
- When you are tired, get some rest. If you feel stressed, try to find a way to relax.
- If you are feeling sad or anxious, talk with someone you trust about it. Many women experience what you are so there is hope!

- Accept that your normal routine is changing.
- Always ask questions if you think that a pain or feeling is not a normal part of pregnancy.
- Nutrition is important during pregnancy. It may even be recommended to avoid some food! Women, Infants & Children (WIC) can help you understand nutrition during pregnancy and even provide eligible participants with vouchers for healthy food during pregnancy.

This is an exciting time and it is important to understand what you should expect during pregnancy. Visiting your health care provider is very important during these early stages. Your health care provider will perform several tests to check the health of both you and your baby. She/he will also be able to answer questions about any concerns or fears you might have, and she will tell you what you can do to make your pregnancy as easy as possible.

You can ask about:

- what types of exercises you can do?
- what you should eat for good nutrition?
- what you might need to avoid during this time?

**Your healthcare provider may have educational materials or go to  
[www.womenshealth.gov](http://www.womenshealth.gov)**

## POSITIVE LIVING

### Things you should know...

- If you were already on HIV medicines at the start of your pregnancy, your medical team will continue the same medicines as long as the medicines are safe for the unborn baby.

Living with AIDS is an experience filled with immense irony—the loss, hurt, sadness, and anger of it all. At the same time, you find countless examples of boundless human will, spirit and compassion at their most brilliant.

*-Russ Radley*

- If your current HIV medicines need to be changed, your medical team will discuss the different HIV medicines known to be safe for use in pregnancy and change you to a safer combination.
- If you are not on HIV medicines at the start of your pregnancy, your medical team will start your HIV medicines at week 13 of your pregnancy.

Some pregnant women vomit (or “throw up,”) due to what is sometimes known as morning sickness in early pregnancy. Some doctors suggest that women interrupt their treatment during the first three months of pregnancy for two reasons:

1. Nausea and vomiting may cause you to lose your medication doses
2. The HIV may develop resistance to the medications that you are taking.

*Ask your doctor how to reduce nausea during this time or what to do if you vomit or throw up your medications.*

## **THE SECOND TRIMESTER**

Most women find the 2nd trimester of pregnancy to be easier than the 1st trimester, but it is important to stay informed about your pregnancy. By the 26th week, your baby will weigh almost 1 1/2 pounds and be about 9 inches long. With this growth comes the development of your baby’s features, including fingers, toes, eyelashes and eyebrows.

The second stage of your pregnancy causes more noticeable changes to your body, relief to problems caused in the first trimester, new changes, and more exciting experiences.

- Morning sickness, fatigue, and many other things that might have bothered you during the first 3 months might disappear as your body adapts to the growing baby.
- Your abdomen will expand as you gain weight and the baby continues to grow.
- If you are feeling sad or anxious, talk with someone you trust about it. Many women experience what you are so there is hope!
- Before this trimester is over, you will feel your baby beginning to move.



You should be gaining about 3 to 4 pounds per month during the 2nd trimester. With this weight gain, you might notice that your posture has changed or that you are having backaches. Make sure to inform your health care provider of any changes you might have noticed.

During your visits your health care provider will be able to hear your baby's heartbeat, see the baby's development and determine the baby's age. You might be given several kinds of tests at this time, including ultrasound, which allows the health care provider to see your baby and possibly even determine your baby's sex. Other testing (chorionic villus sampling, alpha-fetoprotein screening) includes ways to determine if the baby is healthy or if you are at risk for any complications and need to be more closely monitored. These tests help to determine the type of care you will be receiving for the rest of your pregnancy.

If you were not on HIV medicines at the start of your pregnancy, we will start your HIV medicines at week 13. **It is very important that when you start your HIV medicines that you do not miss or skip doses.** If you start having any side effects, or the medicine makes you sick, please call or come to the clinic to discuss your problems taking the medicine.

The goal of HIV therapy is to reduce the amount of HIV in your blood (viral load). Reducing the amount of HIV will keep you healthy and reduce the risk of giving HIV to your unborn baby.

## **THE THIRD TRIMESTER**

It might be hard to believe, but you are in your final trimester of your pregnancy! This means that in a few short months you will be holding your new baby in your arms.

Your baby is still growing and moving, but now it has less room. You might not feel the kicks and movements as much as you did in the 2nd trimester. You will also notice that you may have to go to the bathroom more often or that you find it hard to breathe. This is because the baby is getting bigger and it is putting pressure on your organs. Don't worry, your baby is fine and these problems will subside once you give birth.

During this final stage of your pregnancy, your baby is continuing to grow.

- By the end of your pregnancy you should have gained about 25 to 30 pounds. About 7 1/2 pounds of that weight should be the baby.
- Even before your baby is born it will be able to open and close its eyes and might even suck its thumb.
- Be sure to continue to visit your health care provider, and ask her to answer your questions and address your concerns about labor and delivery.
- Your baby should be moving into its birth position, and your body will be preparing for the birth. Your health care provider can check your progress with a vaginal examination.
- As the birth of your baby gets closer, you and your health care provider will discuss what kind of delivery you will have. Some women need to have a cesarean section (C-section), in which a surgical incision is made to remove the baby. If you are able to plan on a non-surgical vaginal birth, you may want to have your baby naturally, without medications, and you may want to take a childbirth class.

## POSITIVE LIVING

In your third trimester, you may still have questions. That is understandable because more changes are occurring within your body! Ask a member of your healthcare team for information about the following:

- Changes in your mind and body
- Exercise and Kegel exercises
- Fetal development
- Nutrition
- Preeclampsia and pregnancy complications
- Sexuality
- Substance abuse
- Prenatal screening and test

My AIDS diagnosis got me in gear to change my life. While shoveling out from under the pile of garbage I had dumped on myself, I discovered the light within us all. Sisters and brothers, we are love, and love heals.

*-Steven Liposki*

**It is very important that you do not skip or miss doses of your anti-HIV medicines during this last trimester of your pregnancy. The lower your HIV viral load is at the time of your delivery, the better chance your baby will be HIV negative.**

After the delivery of your baby, it is important for you and your healthcare provider to discuss if you will need to continue taking your HIV medicines. This will be discussed in more detail in Section Four, *After the Baby Goes Home*.

## **THE BIG EVENT!**

### **FAMILY PLANNING**

Before the baby is born is a great time for you and your partner to decide if you are ready for additional children. Remember, it is your choice if you want to become pregnant again. If you are not ready for more children, there are several options for contraception or you may even be interested in sterilization. You should talk with your healthcare team about what is right for you. If you aren't sure, you can always talk with them about your options!

***No matter what you choose to do, you will always need to use condoms to prevent transmitting HIV.***

Since you should NOT be breastfeeding, remember that a woman who DOES breastfeed may get her period and become pregnant immediately.



## **PREPARING FOR THE NEW BABY**

Your baby is on the way, and there is so much to do. You will need baby furniture and clothing for your new son or daughter. **Check to make sure that everything is safe—no loose ends, sharp edges or small harmful parts.**

Health care is also something to consider before the arrival of your new baby. Because babies need check-ups and sometimes get sick, you will want to choose a health care provider to care for your child. You might want to call and request an interview with a few pediatricians; this is commonly done. Just like you, your baby will need health coverage. If you think you can't afford it, there are programs available to children who would otherwise have no health insurance. Decide on health care and insurance before your child's birth to save time and ensure that a health care provider will be there when your baby needs care.

Ask a member of your healthcare team to help you find resources to help you prepare for your new baby. There are many things that need to be done before the baby comes home!

Decide on healthcare and insurance before your child's birth.

You have a lot to prepare before your baby is born. You may want to begin purchasing clothing, a car seat and furniture. Don't forget about the daily items your new baby will need, such as diapers, wipes, wash clothes, bottles and more!

Ask your case manager or social worker to help you create a baby checklist of supplies you will need.

- ✓ Clothing
- ✓ Bottles
- ✓ Diapers
- ✓ Formula
- ✓ Crib
- ✓ \_\_\_\_\_
- ✓ \_\_\_\_\_
- ✓ \_\_\_\_\_
- ✓ \_\_\_\_\_
- ✓ \_\_\_\_\_

Please ask any questions you may have about you baby going home:

- Immunizations
- Postpartum depression or anxiety
- Postpartum health
- Day care
- Infant HIV care

### **Prenatal and Parenting Classes**

Your pregnancy and your baby do not come with an instructional manual! Many resources like this book will help you know a lot and help you make decisions. Ask your case manager or social worker about resources in the community that focus on new moms!

Look for classes or resources like:

- Labor and delivery
- Fitness and pregnancy
- Family planning
- Love and Logic
- Quitting drugs and alcohol
- Quitting smoking
- Healthy eating/nutrition
- Lamaze

# CHILDBIRTH

Soon, you will experience the amazing process of childbirth! It is important to recognize the signs of labor so that you will know when you are experiencing the “real thing.”

If this is your first baby, you will most likely experience lightening (the descent of the baby’s head into your pelvis) sooner than women who have already had other children.

Typical signs of labor include:

- Uterine contractions
- Tightening of your stomach
- Cramps in your low back

Your health care provider will describe the labor process, so you will know when it is happening.

You may also be interested in taking childbirth preparation classes, which emphasize minimal medical intervention, teach coping methods for labor and delivery, and help to guide new parents in the many decisions they will make before and during the birth process.

One of the things you may be most concerned with is the amount of pain you may experience during labor. Childbirth is different for all women, and no one can predict how much pain you will have. During the labor process, your health care provider should ask you if you need pain relief, and will help you decide what option is the best for you. Your options may include:

- Local or intravenous analgesic (pain relieving drug)
- Epidural (injection which blocks pain in the lower part of your body)
- Spinal anesthesia (used when the delivery will require forceps)
- Pudendal block (numbs the vulva, vagina and anus during the second stage of labor and during delivery)

Your progression through the different stages of labor and delivery will determine how quickly the baby is coming, and whether you have time to get to the hospital, birth center, or back home to deliver. Having information about your choices for birthing will help with some of the stress you may feel during labor.

Your OB doctor will want to give you an IV of AZT (an HIV medicine) right before the baby is born. This is another way of reducing the amount of HIV in your blood and further decrease the risk of giving HIV to your baby. After your baby is born, the baby should be given AZT syrup by mouth every 12 hours for 4 – 6 weeks. This will also reduce the risk of the baby acquiring HIV.

### **What should I expect during a Cesarean Section Delivery?**

In a cesarean section delivery (sometimes called a C-Section), a surgical incision is made in the mother's abdomen and uterus (womb) to deliver the baby. If your doctor does perform the C-Section, the following steps will be taken to ensure your comfort and safety:

- Your abdomen will be washed and shaved before surgery.
- A catheter (tube) will be placed in your bladder to empty it.
- A small tube will be placed in a vein of your arm or hand to provide fluids and medications during surgery.
- You will require an anesthesia, such as a spinal block.
- Your doctor will make an incision in the abdomen and uterus and deliver the baby through an incision.
- The uterus will be closed with stitches that later dissolve on their own and stitches or staples will be used to close the abdomen.

After delivery, you and your baby will be given a room in the hospital where you will be monitored and cared for. Cesarean delivery is a major surgery, but sometimes is the safest way to deliver a baby.

## **HIV Medications at delivery and after:**

- You will likely receive Zidovudine (AZT) 2mg/kg IV for one hour then 1mg/kg per hour until the baby is delivered.
- You will need to continue your HIV medications until told to stop by your HIV provider.
- Your baby will likely take AZT suspension every 12 hours for four to six weeks. Your medical provider will give you a prescription that is recommended and tailored to your baby.

## **POSITIVE LIVING**

### **AFTER THE BABY GOES HOME**

Your baby is finally here! The joys and challenges of motherhood are about to begin. It is important to remember to take care of yourself as well as your new baby. Caring for a new baby can be fun but it is also hard work. How much and how often should you feed the baby? What do you do when the baby is crying, or sick? How do you prevent accidents?

These questions can be overwhelming at first, but you will quickly adjust. A new baby needs constant care, but you will be skilled at taking care of your child in no time. There are people out there, including your family, friends, health care provider, and support groups, that will help you get through it.

You are not alone. You have experienced nine months of changes in your body. Those changes will continue in the next couple of months as you decide whether or not to breastfeed and as your body starts to recover from having the baby. It is important to follow your health care provider's advice and take care of yourself during this time. Make sure to rest when you can and don't try to do too much.

AIDS has been a mixed blessing for me; it has transformed my life in many ways. In the two years since I found out that I carry the HIV virus, I have learned more about myself than ever before. I also have more love in my life than I ever thought possible. My positive diagnosis brought my family back together at a time where we were beginning to grow apart. It's a good feeling to know how much my family and friends love and support me.

*-Pamela Shaw*



The effect of pregnancy and labor on a woman's body can be tremendous. If you are trying to lose some additional pregnancy weight, make sure you do it in a healthy way and consult your health care provider before you start any type of diet or exercise plan.

### **Is feeling sad, depressed or anxious normal?**

In addition to the physical changes to your body, you may feel depressed. This can be a very normal phase following childbirth. Fifty to seventy-five percent of mothers feel a little sad, anxious or depressed after giving birth. These feelings can range from very mild to serious, but there is help. Be aware of your feelings and continue to talk with your family, friends, and your health care provider. Sometimes this depression will go away on its own, but medication or therapy may be needed. Both can help you feel better and get back to enjoying your new baby. Here are some questions that you should talk with your family or case manager about:

- How are things at home?
- How do you feel about your pregnancy?
- Do you feel like yourself?
- If you have the opportunity to sleep, do you?
- How is your energy level?
- Do you have more bad days than good?
- Do you find yourself being panicked or crying for no reason?
- Have you thought things or seen images in your head that scare you?

### **Feeding Baby**

Breastfeeding is often recommended by WIC Clinics, books, family members and magazines, but breastfeeding risks HIV transmission. The decision to breastfeed is one you will have to make, but remember it is not recommended by your HIV provider.

Here are some things to consider about feeding your baby:

- Family members or friends may ask you why you aren't breastfeeding if you choose not to.
- The WIC program can help pay for formula for your baby.
- You will have to make sure that the formula is not expired or spoiled.

Feel free to ask your case manager about the things above and talk with them about some solutions.

## My Medical Team and Contact Information

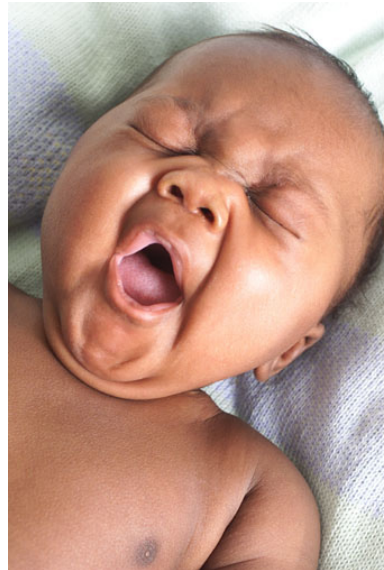
My OB Case Manager is:	Phone:
My HIV Case Manager is:	Phone:
My OB Clinic is:	Phone:
My HIV Provider is:	Phone:
My Pharmacy is:	Phone:
My Baby's Pediatrician is:	Phone:
My Baby's HIV Provider is:	Phone:
My Baby's Pharmacy is:	Phone:

## Resources available through Ryan White Case Management

Ryan White case managers can assist clients in accessing a multitude of resources during pregnancy. Ryan White funds can be used to assist clients with needs such as transportation, mental health support, the cost of HIV related outpatient care, emergency assistance, housing, dental treatment, vision care and informational material about both HIV and pregnancy. In addition to this, Ryan White Family case managers can provide support to family members who are struggling with an HIV diagnosis.

Ryan White Family Case Managers connect you with resources like:

- WIC
  - Food Stamps
  - Medicaid
  - Emergency assistance
  - Shelters-Homeless or Domestic Violence
  - Substance Abuse Treatment
  - Day Care
  - Legal Services
  - Food Pantries
  - Support Groups
  - Mental Health
  - Baby Supplies
- and much more!!



**Helpful numbers to have for assistance:**

Division of Family Services (food stamps/Medicaid/TANF)	816-889-2000
Legal Aid Services	816-474-6750
TMC Hospital Hill (Main Line)	816-404-1000
TMC Hospital Hill - OB Clinic	816-404-4100
TMC Hospital Hill - WIC	816-404-0660
TMC Hospital Hill - ID Clinic	816-404-1885
TMC Hospital Hill - Social Services	816-404-3200
TMC Hospital Hill - Patient Accounts	816-404-2925
Section 8 Housing	816-968-4100
United Way - referrals to many resources	211 or 816-474-5112
Emergency	911
Kansas City Health Department	816-513-6008
Kansas City CARE Clinic	816-753-5144
Childhelp Hotline	1-800-422-4453
Parent Crisis Hotline	1-800-448-3000
Domestic Violence Hotline	1-800-799-7233
Post-Partum Hotline	1-800-944-4773

## GLOSSARY

### A

**Adherence** - The ability of a patient to follow a prescribed medical treatment, including correct dosage, number of doses per day, and dietary restrictions. This is very important with HIV medicines during pregnancy or HIV medicines for babies.

**Alpha-fetoprotein screening (AFP)** - This blood test measures the levels of a substance called alpha-fetoprotein in the mother's blood. Abnormal levels can indicate a brain or spinal cord defect, the presence of twins, a miscalculated due date, or an increased risk of Down syndrome.

**Analgesic** - Agent that reduces pain without reducing consciousness.

**Antibody** - A substance that the body makes to fight any substance foreign to the human body, such as germs.

**Antiretroviral** - A drug that can help slow the progress of HIV disease in some people.

**Asymptomatic** - without symptoms of a disease or illness.

### B

**Birth Center** - A special place for women to give birth. They have all the required equipment for birthing, but are specially designed for a woman, her partner, and family. Birth centers may be free standing (separate from a hospital) or located within a hospital.

### C

**CD4** - A T-cell or part of the immune system that is attacked by HIV. CD4 cells (T cells) are also called helper cells.

**Cesarean section (c-section)** - When a woman cannot deliver a baby vaginally, or if a baby is in distress during labor, a cesarean section is performed. An incision is made in a woman's abdomen and her uterus to deliver the baby.

**Clinical trials** - AIDS Clinical trials are research studies in which new therapies for AIDS and HIV infection are tested.

**Contractions** - The tightening and shortening of the uterine muscles to aid in the descent of the baby into the birth canal. This begins labor.

## D

**Drug interactions** - Incidents that occur in the body when a medication is affected by another medication.

## E

**Epidural** - During labor a woman may be offered an epidural, where a needle is inserted into the epidural space at the end of the spine, to numb the lower body and reduce pain. This allows a woman to have more energy and strength for the end stage of labor, when it is time to push the baby out of the birth canal.

**Episiotomy** - This is a procedure where an incision is made in the perineum (area between the vagina and the anus) to make the vaginal opening larger in order to prevent the area from tearing during delivery.

## I

**Intravenous analgesic** - An analgesic is a drug that relieves pain. During labor, a woman can be given pain-relieving drugs intravenously (through a tube inserted into her vein).

## L

**Lamaze** - There are different techniques for preparing for childbirth and Lamaze is one of them. It was developed by Dr. Ferdinand Lamaze and is based on the idea that being relaxed and knowing what is going to happen are the best ways to control pain during labor and delivery. Lamaze teaches women different breathing techniques to use during different stages of labor to stay relaxed and focused.

**Local analgesic** - An analgesic is a drug that relieves pain. Pain-relieving drugs can be given to a woman during labor and delivery locally through a needle inserted into a muscle (intramuscular) or under the skin (subcutaneous).

## N

**Nurse-midwife** - A nurse who has undergone special training and has received certification on birthing (labor and delivery). Nurse-midwives can perform most of the same tasks as physicians and have emergency physician backup when they deliver a baby.

## O

**Ovulation method** - This is a natural planning method women can use to become pregnant. With this method, a woman has sexual intercourse just before or after ovulation (when eggs are released from the ovary) in order to become pregnant. Ovulation is determined by examining how much mucus is being produced by the cervix (or opening of the uterus) and how it feels. A woman looks at her cervical mucus (at the opening of her vagina) on a regular basis and learns to identify the changes in her mucus at the time around ovulation.

## P

**Perinatal transmission** - Passing disease from mother to baby in the uterus or during/after birth.

**Protease Inhibitors** - Medicines that attach to block HIV enzymes, during the last stage of viral replication. In order to prevent production of new HIV viruses.

**Pudendal block** - This procedure anesthetizes, or numbs, the area around the vulva to reduce pain during labor and delivery.

## S

**Serum bilirubin** - A normal substance produced when red blood cells come to the end of their life span and break down. This is usually passed in the stool. Too much bilirubin in the body causes jaundice.

**Symptothermal method** - This method combines two methods of natural family planning, the basal body temperature method and the ovulation method (see ovulation method defined above). With the basal body temperature method, a woman takes her temperature every morning before getting out of bed and records it on a chart. She plots her temperature over time, noting any rises in temperature. A rise in body temperature means that ovulation has occurred and she can have sexual intercourse to become pregnant. With the symptothermal method, both changes in cervical mucus and body temperature are monitored, along with looking for other signs of ovulation such as breast tenderness, vaginal spotting, and abdominal cramps.

## T

**Teratogenic** - Able to produce abnormalities in a developing fetus, that is, causing birth defects.

**Trimester** - A typical pregnancy is 9 months long. Pregnancy is divided into three time periods, or trimesters, that are each about three months in duration - the first, second, and third trimesters.

## U

**Ultrasound** - This screening is done with equipment that uses high-frequency sound waves to form pictures of the fetus on a computer screen. The test can verify due date; determine causes of bleeding; check the overall health, development, sex, and position of the baby; measure the amniotic fluid; and check the condition of the placenta.

**Universal Precautions** - Methods used to protect people from exposure to other people's bodily secretions. Such exposure could be dangerous. Bodily secretions include blood, semen, urine, vaginal fluid and bowel movements. Universal precautions should be practiced with all people in all areas where care is being offered, including hospitals, day care centers, etc.

**Uterine contractions** - During the birthing process, a woman's uterus tightens, or contracts. Contractions can be strong and regular (meaning that they can happen every 5 minutes, every 3 minutes, and so on) during labor until the baby is delivered. Women can have contractions before labor starts; these are not regular and do not progress, or increase in intensity or duration.

## V

**Vaginal Delivery** - Birth of the baby through the vagina.

**Vertical Transmission** - Passing a disease from mother to baby in the uterus or after birth (also called perinatal transmission).

**Vulva** - This term refers to the external genital organs on a woman. It includes the labia (the "lips" around the opening of the vagina) and the clitoris (a small mass of tissue at the opening of the vagina that helps a woman achieve orgasm during sexual intercourse).



