

You've just been diagnosed with HIV. What do you do next?

- Begin with your health care professional
- Use this booklet
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The Complete HIV/AIDS Resource



HIV & Me

A Woman's Guide to Living With HIV

A special report from TheBody.com



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Consult your doctor! The only purpose of this booklet is to educate and to inform. It is not a substitute for professional care by a doctor or other medical professionals. TheBody.com neither endorses nor opposes any particular treatment option discussed in this booklet. Instead, we encourage you to discuss your options with a health care provider who specializes in treating HIV. We would like to thank Sharon Dian Lee, M.D., for providing a medical review of this booklet.



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Did You Just Test HIV Positive?



We don't want to make light of **what you're going through**. Getting an HIV diagnosis may feel like the worst thing that has ever happened to you.

BUT PAY ATTENTION TO THIS: *There is life after testing positive.* One million Americans are now living with HIV, and approximately 25 percent of those newly diagnosed with HIV are women. Yes, that's right: *women*. In fact, although women with HIV may seem invisible, there are more than 126,000 women living with HIV in the United States.

SO, TAKE A DEEP BREATH. No matter how alone you may feel right now, know that there is a big community of HIV-positive women out there ready to provide information, support, advice and many other resources. In this booklet, you'll meet some of these women. We hope they will help you **fight the fear**, ignorance and prejudice about HIV and HIV-positive people that unfortunately still exist. We hope you'll use this booklet to **learn more** about HIV—and to discover some helpful steps you can take to live a full and happy life with HIV.

STEP

1

Getting Smart About HIV

Once you find out that you are HIV positive, one of the most important things you can do is get informed.

THE FACTS ABOUT HIV: There are hundreds of different kinds of viruses in the world. Some are just annoying, like the viruses that cause colds. Others, like HIV or the hepatitis C virus, can cause serious, even life-threatening, illnesses. By taking care of your body—which includes taking HIV medications that can control HIV—you can prevent many HIV-related illnesses.

WHAT HIV DOES TO YOUR BODY: The reason HIV is dangerous is that it sets up shop in your immune system, your body's natural defense against disease. It especially targets your "CD4 cells," also called "T cells," which your body uses to fight infections. HIV takes command of these cells—like a pirate taking over a ship—and uses them to reproduce itself, creating millions of new viruses every day and slowly weakening your immune system, which can put you at risk for developing potentially dangerous illnesses.

The stronger your immune system, the longer it can keep up the fight against HIV. If you treat your immune system well—especially by reducing stress, avoiding alcohol and not smoking cigarettes or using recreational drugs—your immune system may be able to keep HIV in check for years.

But even if you treat your body well, HIV can still eventually get the upper hand. Then it's time to call in the big guns: HIV medications. We'll talk more about HIV medications later. First, let's dispel some myths about HIV.

“I eat right. I don’t drink. I don’t smoke. I don’t do drugs. I try my best. ... I want to do everything right. I want to be there for my baby. I want to see her graduate from school.”

— Fortunata Kasege, diagnosed in 1997, mother of a 10-year-old, HIV-negative daughter



Myth Versus Reality

Even though the facts about HIV are well known and agreed upon by every HIV specialist and every single HIV/AIDS organization in the United States, there remains a lot of misinformation about HIV.

MYTH: HIV can be transmitted through everyday contact.

REALITY: There are absolutely no documented cases of HIV being transmitted casually through handshakes, hugging, sharing cups or dinner plates or using the same bathrooms.

MYTH: HIV doesn’t cause AIDS.

REALITY: After 25 years, there is a mountain of proof that HIV causes advanced HIV, also known as AIDS. Everyone who ever got sick or died from AIDS had one thing in common: They had HIV.

MYTH: HIV-positive women should not get pregnant.

REALITY: More and more women with HIV are giving birth to healthy HIV-negative babies. By working with an HIV-experienced obstetrician, an HIV-positive woman can reduce the risk of passing the virus to her baby to one or two percent.

MYTH: There’s a cure for HIV, but only the rich have it.

REALITY: If rich people had a cure

for HIV or AIDS, Magic Johnson, who is a multimillionaire, would be cured. Yes, Magic looks fantastic and—even with HIV—is healthier than many HIV-negative Americans. But that’s because he takes care of himself and is on HIV treatment—the exact same treatment available to everyone with HIV in the United States. Magic’s wife, Cookie, has admitted that she was wrong to say that he was “cured.” She meant that the medications he was taking had gotten rid of almost all the virus in his body, but he still remains HIV positive.

MYTH: Taking HIV meds means you don’t have to practice safer sex.

REALITY: The drugs can get rid of nearly all the virus in your blood. Although this will decrease the risk of infection to your sex partners, blood and vaginal fluids still contain HIV. This means that protected sex is the rule to keep your partner safe. Plus, you can get in serious legal trouble if you don’t tell your partner about your HIV.

STEP

2

Telling Others

How do you tell friends or family that you have been diagnosed with HIV? It's one of the greatest challenges you'll face—and it's not something to rush into if you're not ready. There are some important personal steps you should take before you disclose your status to others.

FORGIVE YOURSELF

HIV is a loaded term: An ignorant world has wrongly stuffed those three letters full of shame and judgment. But no matter what anyone tells you, **HIV is not a punishment for sin or immorality.** Having HIV is not a crime. HIV is just a virus that causes a disease. It does not discriminate. Anyone can get it.



"In the beginning, I couldn't forgive myself for getting HIV," remembers Heidi Nass, who was diagnosed in 1996. "I felt compassion toward other HIV-positive women, regardless of what led them to their infection, but I could not find it for myself."

This changed for Heidi when she spoke with a close female friend, who had gotten HIV long ago from using dirty needles

when shooting drugs. Her friend counseled, "If you're looking for reasons to feel shame, you'll always be able to find them. At some point, though, you might want to look for something else ... like forgiveness." That is the moment that Heidi remembered something she had forgotten: "Forgiveness is something we choose; it only happens when someone chooses it."

GIVE YOURSELF TIME

There's no rule of thumb that can tell you how long you will need to come to terms with your HIV diagnosis. Some women need a few weeks or months; for others, it can take years.



For Theresa Parrish, who was diagnosed with HIV in 1989, it was a full year before she learned how to forgive herself, "I realized that I

“Someone who is grateful for your presence in this world is going to hold you closer, not push you away, because you have HIV.”

— Heidi Nass, diagnosed in 1996



hadn't done anything so terrible to get HIV." It was not an easy year. "It's the stigma that goes along with HIV. That's where the guilt and the shame came from," she says. "The first few months were hell. I was searching for answers, and searching for, 'Why me?' and 'How could this happen?'"

So give yourself time. Everyone adjusts in her own way. **Let yourself have the time and space you need to find the answers you're looking for.**

SEEK OUT SUPPORT

Once you have taken the time to get used to your new status, an important step to take is to find someone you can confide in—someone you can trust who will be there when you need them. As women, we're often too busy taking care of other people to even realize that we might need help taking care of ourselves. However, emotional support is essential for your survival. Of course, figuring out in whom to place that trust can be a difficult decision.

If you have no one in your immediate circle, read Step 3 and contact one of the resources listed on page 9. Once you feel confident that you've got a

base of support, you can begin to reach out to the people you weren't ready to talk to at first.

Of course, there is no reason to tell everyone you know that you have HIV. The only person you are obligated to reveal your status to is your sexual partner. It's no one else's business—not your friends, not your family, not your boss or your coworkers. However, you may decide that it's an important part of your own healing process to disclose your status to others, regardless of how they might react.

Ultimately, by forgiving yourself, giving yourself time and seeking out support, you'll be able to get to a place where HIV is just another part of your life—not what defines your life.



Desiree Herron reveals that after her diagnosis, she discovered an aspect of herself that she never knew existed. "In some ways," she says, "HIV has been a blessing. It's made me extremely courageous, extremely strong."

Name: **Sarah**
CD4 Count: **123**
Viral Load: **142**
Diagnosed: **1994**
Age: **24**

Job: **Works for her family's business**



SARAH has been living with HIV her entire life. Her mother was given a blood transfusion after Sarah's birth via a C-section, and the blood was infected. Her mother and then her father acquired HIV, as did Sarah after she was breastfed. As a girl growing up in a small, conservative, religious community, she faced all the burdens of what was in the 1980s "a very scary kind of epidemic."

"Even now," she explains, "people aren't that understanding about HIV, but in the '80s and '90s it was a lot worse." She remembers HIV-positive people being told they couldn't go in the swimming pool and even people being forced to move. "Also, HIV was considered a disease that was in the homosexual community," she recalls. "My parents are pretty conservative religious

people, so for them to have the disease was ten times worse."

Sarah feels HIV took away part of her childhood, forcing her to "face stuff that is hard for grownups to deal with." Dating in her Christian high school was another tough hurdle for Sarah. The boys didn't mind her HIV status, she says, but their parents were uncomfortable and sometimes mean about it. At one point, her dad posted her profile on an online dating site to help her meet boys.

These days, she looks to her husband (who is HIV negative), family and friends for support and says she would like to be more involved with HIV-positive children: "I know that I would have loved to have been able to see someone who went through it as a child and could still do pretty much normal things as they got older." 🌸

Getting Connected to Support

No woman should face an HIV diagnosis alone. So, whatever your reservations, make sure you connect with a community of HIV-positive people. It's a key step towards solving both the emotional and practical problems of living with HIV.

Knowing when you need help is vital. An HIV/AIDS organization can be a life-line. Many HIV/AIDS organizations have case managers who can help you move forward on many of your health care issues.

You'll find most, if not all, of the following at HIV/AIDS organizations:

- HIV support groups
 - Mental health and substance abuse counseling
 - Case managers who can connect you to government aid you may need, such as Medicaid, disability insurance or medication assistance
 - Expert information on HIV and nutrition, fitness and other issues
 - HIV treatment information and adherence workshops to help with taking HIV medications
- HIV prevention counseling, safe sex workshops and free condoms

Most big cities have several HIV/AIDS organizations geared to meet the needs of different populations. For help in finding a local organization, go online to www.thebody.com/hotlines.html or call the CDC Healthline at 1-800-232-4636.

For additional information on finding support and information available for someone diagnosed with HIV, visit: www.thebody.com/justdiagnosed

“An HIV support group was really what kept me positive and focused on living with the disease, and not dying from it.”

— Pam Yelsky, diagnosed in 1992



Name: **Teniecka Hannah**
 CD4 Count: **477**
 Viral Load: **Undetectable**
 Diagnosed: **2001**
 Age: **26**
 Job: **College Student**



Boutte's Photography

TENIECKA trusted her boyfriend of two years. She was monogamous and thought he was, too—until she tested positive for HIV in 2001, and also discovered that her boyfriend was married.

It took Teniecka a full year to wrap her mind around being HIV positive and to seek the support of an HIV/AIDS organization.

Although her family had a difficult time coping with the news, they now are her biggest source of support. Her faith also helped her get through the tough time after her diagnosis.

She wants people to know that, “Yes, there is life after testing HIV positive. Yes, you will feel very terrible at first, but life doesn’t stop after your diagnosis.”

“Since testing positive for HIV, I look at the world from a very new

perspective. Life is a precious treasure and, if taken lightly, can be gone in moments. I am especially thankful, honored and blessed to have an opportunity to help and not just sit back. At the end of the day, I want to know I made an impact on someone.”

From believing HIV was an automatic death sentence, and that there was nothing for her to do, she has become a student at Colorado Christian University, and plans to eventually get her master’s degree in business management.

Teniecka has also toured the United States speaking about being HIV positive and the importance of getting tested. Plus, she’s recently fallen in love. She and her HIV-negative fiancé are planning their wedding and expecting their first child. 🌸

Women's Resources

As we've mentioned, HIV/AIDS organizations can provide a lot of help. There are even a growing number throughout the United States that specifically cater to the needs of HIV-positive women and offer a range of services.

Call the **24-hour CDC HEALTHLINE** at 1-800-232-4636 for referrals to organizations near you. No matter where you live, you can also call one of the organizations below to connect to other HIV-positive women and find services.

WOMEN ALIVE (Los Angeles, CA)

The country's largest organization helping HIV-positive women. Their hotline is open 10 am – 6 pm (Pacific time) Monday – Friday
1-800-554-4876

WORLD (Oakland, CA)

One of the oldest organizations devoted to HIV-positive women. Great newsletter and yearly retreats.
1-510-986-0340

CHICAGO WOMEN'S AIDS PROJECT

They have a wide array of services for HIV-positive women in Chicago.
1-773-271-2242

WOMEN'S INSTITUTE (New York, NY)

Services for women at GMHC, the largest HIV organization in NYC.
1-212-367-1365

WOMEN AT RISK (Culver City, CA)

They specialize in helping women in the Los Angeles area, but can offer resources to women throughout the U.S.
1-310-204-1046

BABES NETWORK (Seattle, WA)

One of the oldest organizations helping HIV-positive women. Their hotline is open 10 am – 6 pm (Pacific time)
1-888-292-1912

WOMEN AND AIDS NETWORK (New Jersey)

Their Warmline is open 9 am – 5 pm (Eastern time) Monday – Friday
1-800-747-1108

HIV WISDOM FOR OLDER WOMEN

Help for HIV-infected older women.
1-816-421-5263

STEP

4

Finding Quality Health Care

Even if you don't yet need treatment, it's essential that you find a medical professional who is experienced in treating HIV-positive women. Regular checkups with an HIV health care provider are extremely important, even when you don't feel sick.

You'll need to find a health care provider (this could be a physician, nurse practitioner or physician assistant) with special training in HIV who has treated 20 or more people with HIV, in the past two years. You'll want someone who stays on top of the newest information about HIV medications, tests and other issues. You'll also want someone who has extensive experience treating women with HIV.

However, it's just as important to choose someone you like, someone you feel you can trust and be open with. This means you'll need to find someone you can be

honest with about sensitive issues—everything from sex, drugs and alcohol use to missing doses of HIV meds.

Your health care provider is your partner in fighting the virus. She or he will be your ally for a long time, helping you deal with the ups and downs of HIV disease, the drugs that control the virus, the side effects that may come with the drugs, and many other health issues.

There's a nationwide network of services, programs and resources to help people with HIV remain healthy—even



"My HIV specialist and I have a good relationship. We are like equal partners, where he tells me everything I need to know medically, but I make the final decisions. He has both compassion and great knowledge of HIV."

— Joyce McDonald, diagnosed in 1995

“I believe diet and exercise are extremely helpful. I believe you have to participate in the solution, and not wait for somebody to hand you the answer in a pill, or a shot.”

— Sherri Lewis, diagnosed in 1987



people who have no insurance or low incomes.

Many big cities have state-of-the-art HIV clinics for people who have no insurance. When you enroll in these clinics, you get medical care from a top team of HIV health care providers as well as counseling and support for mental health, substance abuse and other issues. You may be assigned to a case manager, who will become the person you can turn to first for whatever help you need—such as figuring out which government programs can pay for your HIV medications and HIV care.

Live in a rural area? Getting the best HIV care possible may mean traveling to the nearest city several times

a year—an extra effort, but one that will repay you with better health.

For a list of HIV clinics near you, call the [CDC Healthline](https://www.cdc.gov/healthline) at **1-800-232-4636**. An HIV clinic will give you better care than other types of health clinics or hospital emergency rooms, since it is staffed by HIV specialists and is equipped specifically to help people with HIV.

Also keep in mind that women with HIV are much more likely to have gynecological problems like irregular periods and abnormal Pap smears. If your HIV specialist doesn't provide gynecological care, be sure to ask your HIV specialist for a referral to a gynecologist who has experience working with HIV-positive women.

“It wasn't an easy road. I got help from a great group of professionals who provided counseling ... I received every service that I could to make sure that I would survive.”

— Fortunata Kasege, diagnosed in 1997 when she was pregnant. Her daughter is HIV negative.



Name: **Cathy Olufs**
 CD4 Count: **Over 500**
 Viral Load: **Undetectable**
 Diagnosed: **1995**
 Age: **43**
 Job: **HIV Educator**



THROUGH much of her youth, Cathy Olufs felt indestructible. In spite of risky sex and years of crack cocaine use, Cathy thought she wasn't at risk for HIV. "Like a lot of other women, I thought that I wasn't at risk because I was heterosexual. I really thought that it was a disease of intravenous drug users and gay men." For a while, she had a lucky streak with testing; that is, until her third test came back positive.

Cathy was 31 at the time. That news sent her right back to her drug of choice, crack cocaine, and soon after, Cathy's addiction landed her in prison. There she was forced to acknowledge that she needed help. Attending an inmate-run HIV support group, she found the inspiration and the guidance to continue her own self-care and to help others like herself. Since leaving prison in 1996, she has given up drugs and has dedicated herself to working with HIV-positive people.

Cathy is now the education director at the Center for Health Justice,

providing HIV education inside correctional settings. Cathy says she found her calling in educating others and motivating by example, as an activist, writer and public speaker.

Since she tested positive, Cathy has also gotten married and completed her bachelor's degree at Antioch University in Los Angeles.

Her health is good, she reports. "Because I have such a broad understanding of HIV and HIV medications, and have seen a lot of people that have had real difficult times with medications, ... I don't fool around. I take my medications as I'm supposed to. I really feel like if it is truly possible to take lemons and make lemonade, that's what I have done. And I enjoy my life. I feel like everything has happened and unfolded the way that it was supposed to. I used to be ashamed of my background, but not so much anymore. I would not be the person I am today if I hadn't walked through all the experiences of my life. I am richer because of it." 🌸

STEP

5

Learning About HIV Treatment

Your HIV-positive test result only lets you know that you've been infected with HIV. To find out if it's time to get HIV treatment, you'll have to visit a health care provider and get two additional tests.

Most HIV-positive people can live many years with HIV before they need to take medications to control it. However, every person who tests HIV positive should immediately have two additional tests: a CD4 count and a viral load test. These tests are the critical measuring tools you and your health care provider will use to see what the virus is doing in (and to) your body.

THE CD4 COUNT TEST

This test, also known as a "T-cell count test," gives an indication of the number of CD4 cells in your bloodstream. The more CD4 cells you have, the stronger your immune system is.

After living with HIV for a while (if you don't take medications), the number of CD4 cells you have will usually fall. This is a sign that your immune system is being weakened.

A normal CD4 count for someone without HIV is usually between 500 and 1,600. Experts generally agree that when your CD4 count goes below 350, you're at a high risk for developing potentially dangerous illnesses, so you should begin taking HIV medications *before* your CD4 count hits 350.

CD4 COUNT EXPLAINED

Healthy	500 – 1,660
Borderline Low	350 – 500
Low	200 – 350
Extremely Dangerous	0 – 200

THE VIRAL LOAD TEST

Viral load tests provide an estimate of how much HIV is circulating in your blood. Generally speaking, your viral load is not considered as critical as your CD4 count in determining the health of your immune system. However, once you begin HIV treatment, it

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Name: **Esmeralda**

CD4 Count: **900**

Viral Load: **Undetectable**

Diagnosed: **1998**

Age: **35**

Job: **Housekeeper**



ESMERALDA (not her real name) discovered that her husband had HIV only after his death, a few days after he had entered the hospital for the first time. The couple had been living in a small Mexican town. At first, his family didn't tell her what was wrong.

She soon discovered that she too had HIV. She was breastfeeding her baby daughter at the time and, to protect her daughter from getting HIV, she was told to stop breastfeeding. She remembers being "really, really scared" for her baby. Fortunately, her daughter was HIV negative. But Esmeralda discovered that she was pregnant again.

Four days after her husband's death, Esmeralda was encouraged to move out. With little money, one baby, and another on the way, she had nowhere to go.

So, she crossed the border into California to live with her sister-in-law. While she was pregnant with her second baby, a boy, she took medicine to prevent the transmission of HIV and didn't breastfeed him either. He is HIV negative.

Esmeralda's life soon took a turn for the better. A social worker, a nurse and a peer advocate helped Esmeralda with services. Through them, Esmeralda met women with HIV who became her good friends. They gave her rides to appointments and supported her.

These days, Esmeralda is happily married to an HIV-negative man. She's doing well medically and she even works full time cleaning houses. On evenings and Saturdays, she takes English lessons. She also volunteers at a women's HIV organization and an HIV clinic. 🌸

“You really don’t have to die from HIV today. You can live with it. I certainly wouldn’t say, ‘Well, la, la, la, all you have to do is pop a few pills every day and you can go about your merry way,’ because that isn’t the truth. There *are* things that are going to change your life, that you’re going to have to do differently.”

— Pam Yelsky, diagnosed in 1992



Learning About HIV Treatment

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is a good measure of how well your HIV medications are working.

A viral load test measures the amount of HIV in a small amount (milliliter or mL) of your blood. Current viral load tests can detect as few as 50 copies of HIV per milliliter of blood. When your viral load test indicates that you have fewer than 50 copies/mL of HIV, your health care provider will tell you that your viral load is “below the limit of detection,” or “undetectable.”

This does not mean that you no longer have HIV in your body. Even someone who has an “undetectable” viral load can transmit HIV. However, an “undetectable” viral load means that your medications are doing an excellent job of keeping HIV in check.

RESISTANCE TESTING

Besides a CD4 count and viral load test, your HIV specialist will look at your overall health with a general blood count test. You may also be

given an HIV drug resistance test. A resistance test will tell you if your HIV has already become resistant to any HIV medications.

How could this happen? The person you got HIV from may have been on HIV treatment and his or her virus may have become resistant to one or more HIV medications. Transmitted along with HIV was their resistance to certain drugs. So before you take treatment, you’ll want to be sure your HIV is not resistant to any drugs.

DEALING WITH HIV AND OTHER ILLNESSES?

Be sure to stay on top of HIV as well as any other infections or illnesses. If you are infected, for example, with HIV and hepatitis B or C, your physician may refer you to a liver specialist who also specializes in HIV. If you are seeing other health care providers, besides your HIV specialist, be sure that they are all in contact.

Pregnancy and HIV

Preferred Anti-HIV Medications for Pregnant HIV-Positive Women

- Retrovir (AZT)
- Efavir
- Vireamune
- Kaletra

Anti-HIV Medications to Avoid if You're Thinking About Getting Pregnant or if You Are Pregnant

- Sustiva
- Atripla
- Videx + Zerit

In the dark old days of the late 1980s and early 1990s, when little HIV treatment was available, having HIV dashed all hopes of motherhood. But today, with the right care, a woman with HIV can expect to lead a long and healthy life. So, if your dream is to become a mother, the likelihood that you'll have an HIV-negative child is greater than it's ever been before. In fact, there's a baby boom among HIV-positive women. What do you need to know about pregnancy and HIV? Here are some answers to frequently asked questions.



"The biggest challenge in being pregnant and HIV positive is the fear and not knowing, because I didn't know whether my son would be positive or not. At first, I was very uneducated about HIV and pregnancy, because I never intended on getting pregnant ... I cried every day, and prayed every day."

— Jessica Mardis, diagnosed in 1995, mother to an HIV-negative son

Pregnancy and HIV: Frequently Asked Questions

I WANT TO BECOME A MOTHER, BUT I'M HIV POSITIVE. WILL MY BABY ALSO BE INFECTED?

The most critical thing is for you to have an undetectable viral load. If your viral load is undetectable, and if you take anti-HIV medication before and during pregnancy and delivery, your baby only has a 1 to 2 percent risk of being infected. If you do not take HIV treatment, the baby has a 20 to 30 percent chance of being HIV infected.

WILL ANTI-HIV MEDICATIONS HARM ME OR MY BABY?

The majority of HIV medications have been shown not to harm babies. Only Sustiva—which is one of the drugs in the one-pill-once-a-day regimen of Atripla—as well as the combination of Videx and Zerit should not be taken by any woman thinking of becoming pregnant. Talk to your doctor about which other drugs may be harmful during your pregnancy. If you are already taking anti-HIV medications, the worst thing you can do is stop taking them without consulting your doctor first.

C-SECTION OR VAGINAL BIRTH?

You can plan for a normal vaginal birth if you have an undetectable viral load.

If your viral load is above 1,000, plan for a C-section. A C-section would dramatically reduce your chance of transmitting HIV to your baby.

WILL PREGNANCY AGGRAVATE MY ILLNESS?

HIV does not progress any faster in HIV-positive women who get pregnant. It's important, however, that you get not only HIV but any other disease, such as diabetes, under control *before* you get pregnant.

WILL MY BABY HAVE TO TAKE HIV MEDICATIONS?

Yes, you will have to give your baby HIV medications for approximately six weeks.

CAN I BREASTFEED?

Breast milk can transmit HIV, so it's recommended that all women with HIV do *not* breastfeed and instead use infant formula.

IS PREGNANCY DIFFERENT FOR HIV-POSITIVE WOMEN?

Research shows little difference between pregnancy in HIV-positive women and negative women. Women taking HIV medications may be more likely to give birth prematurely or have babies that weigh less than average.

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Name: **Fortunata Kasege**

CD4 Count: **380**

Viral Load: **5,000–6,000**

Diagnosed: **1997**

Age: **33**

Job: **HIV/AIDS Advocate**



FORTUNATA was diagnosed with HIV in 1997, while pregnant with her daughter. At that time, she had just emigrated from Tanzania to the United States. “Like anybody who received an HIV diagnosis, I was terrified. I don’t remember being that scared in my life. It’s just a horrifying moment for me. It took a long time for me to recover from this news.” She was married at the time and her husband turned out to be HIV negative. He later left Fortunata and she faced many difficult years.

But a transformation took place in Fortunata’s life and she became a dedicated HIV/AIDS activist. She now volunteers for the Campaign to End AIDS in Houston, Texas, where she lives with her daughter, who is now 10 years old and HIV negative.

Fortunata also often speaks publicly about HIV. She recalls the first time she ever spoke to an audience: “I got an invitation to speak in Kentucky. I remember after I finished, everybody stood up and remained standing for a few minutes, clapping. I was overwhelmed. ... Here I am, telling my business, right in front of people. I didn’t know how they were going to react! The outcome was remarkable. ... The pastor from the community said, ‘People here, they’re very uptight, and very conservative thinking about this disease. You put a new face on it, and thank you.’”

Fortunata gets much of her support from the community of friends she made after her diagnosis. But she says her family in Tanzania is also an important source of support. “They talk to me constantly on the phone,” she says. “They pray for me, and they’re there for me. I’m blessed that way.” 🌸

Pregnancy and HIV: Frequently Asked Questions

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IDON'T WANT TO GET PREGNANT. CAN I TAKE CONTRACEPTIVES?

Various HIV medications interact with oral contraceptives, making them less effective, so you'll need to also use other contraception to avoid pregnancy if you are taking HIV meds.

IS IT HARDER FOR HIV-POSITIVE WOMEN TO GET PREGNANT?

Women with HIV may have a harder time getting pregnant. If you've been trying to get pregnant for a while, you may want to see a fertility doctor experienced with HIV-positive women.

MY PARTNER IS HIV NEGATIVE AND I'M NOT. CAN WE STILL START A FAMILY?

There are many ways to have a baby when you are in a mixed-status rela-

tionship. Although there is no method that is 100 percent risk-free, there are many low-risk options, from the at-home method of using a turkey baster to paying top dollar at a fertility clinic. The key is for the HIV-positive partner to have an undetectable viral load.

HOW DO I FIND AN OBSTETRI- CIAN WHO IS KNOWLEDGEABLE ABOUT HIV-POSITIVE WOMEN?

The best person to ask for a referral is your health care provider, if he or she is an HIV specialist. Otherwise, call the largest HIV organization near you and see if they can refer you to someone. It's crucial to your health and the health of your baby that you find someone with lots of experience helping a pregnant HIV-positive woman.

“The best way for me to learn how to cope with my diagnosis was by learning *everything* I could about HIV. The more educated I became, the less scary the virus was. I also found it extremely important to have people in my life that supported me and that I could talk with openly. Finding out you are HIV positive is an extremely scary thing, but life can and does go on. Since my diagnosis I have given birth to an amazing little boy, gone to college and found love! I have HIV, but it is not in charge of my life.”

— Kelly Hill, diagnosed in 2000



Preparing to Start HIV Treatment

Once your health care provider recommends that you begin treatment, it's important to consider how treatment will change your life. Are you ready mentally, as well as physically, to take medications every day? Remember: Most HIV specialists say that you have to take your medications exactly as prescribed, at least 95 percent of the time, to keep HIV under control and prevent it from becoming "resistant." HIV that is resistant can make your medications less effective.

This means you have to be certain that taking your medications will become a central part of your daily life. Be honest with your HIV specialist about anything that may make it more difficult for you to take all of your medications on time. If you have a case manager or a counselor, talk with them about this important issue as well.

Without a doubt, the commitment to taking HIV medications will be challenging. This is especially true for women, who generally have lots of family responsibilities to deal with.

However, you have a good chance of keeping HIV under control with the very first combination of medications that works for you. If this combination successfully controls your HIV, and if you

take each and every pill as prescribed, you may not have to change medications for a long time. Here are some things to consider:

WHAT IF YOU AREN'T ALWAYS ABLE TO TAKE ALL YOUR MEDICATIONS ON TIME?

This may cause your combination of medications to fail. If this happens, it can get harder and harder to keep HIV under control with each new drug combination. It's crucial to identify a combination you can stick to, *before* you start treatment.

YOUR MEDICATION SCHEDULE SHOULDN'T BE TOO COMPLEX

One thing is certain: Taking medications daily will change your life. This is especially challenging when you are taking care of children. Suddenly, you'll

“Taking medication has just become a routine to me. The regimen I’m on right now: I do it in the morning after I eat breakfast, and in the evening after I eat dinner, and now this is just my routine.”

— Theresa Parrish, diagnosed in 1989



have an additional responsibility. You’ll always have to be aware of the time, your schedule and changes in your routine.

In some cases, you may have to schedule taking your HIV medicine around meals or take it with or without certain foods. Even if you are depressed or busy, you will still have to take your medications as prescribed every single day. So, before you begin HIV treatment, you must ask yourself: “Am I really ready?”

PLAN HOW YOU WILL DEAL WITH SIDE EFFECTS IF THEY OCCUR

All medications can have side effects—even aspirin. Not everyone experiences side effects from HIV medications, which can range from mild to severe. But research has shown that women may be more likely to experience side effects with HIV medications than men. Because you really want to give this first com-

ination your best shot, talk to your doctor and read about the possible side effects of the medications you are thinking of taking. This can help

you not only to plan how to manage side effects if they arise, but to choose medications whose possible side effects you can manage. Be sure to let your doctor know *before* you stop medicines due to side effects.

YOUR SURROUNDINGS AND YOUR MENTAL HEALTH ARE CRITICAL

If you are depressed, using recreational drugs or living on a friend’s couch, it may be unrealistic to assume you’ll be

able to take all your medications all the time.

Remember, it helps a lot to have friends, family, a support group or a therapist you can rely on while you are on a treatment regimen—especially at the beginning when you are still adjusting to taking meds.

IT HELPS A LOT TO HAVE FRIENDS, FAMILY, A SUPPORT GROUP OR A THERAPIST YOU CAN RELY ON.

Choosing the Right HIV Treatment

Doctors have not yet discovered a single combination of HIV medications that's best for everyone. Each combination has its advantages and disadvantages.

For people who are starting on their first HIV treatment combination, each treatment regimen must include at least one drug from two different types, or "classes," of HIV medications. There are currently five classes of HIV medications. Each class of HIV medication stops HIV from making copies of itself at a different moment in its reproductive cycle. You and your provider will consider many issues before deciding on a treatment combination, including:

- Your lifestyle
- Which treatment regimen will allow you to get pregnant, if this is what you want
- Which treatment regimen preserves your future treatment options
- How powerful a regimen it is
- What side effects a regimen can cause
- Other illnesses you may have (such as hepatitis C or high triglycerides), as these can affect which HIV medications are best for you
- Other medications you may need to take (so that you can be sure there are no interactions between the drugs)
- Financial issues, such as what your insurance will pay for



“Do you love yourself enough to take treatment on a daily basis? If you don’t love yourself, you won’t do it.”

— Beatriz Diaz, diagnosed in 1992

STEP

8

Dealing with HIV Treatment

You've made the commitment to begin treatment and settled on your first HIV medication regimen. To ensure that your meds keep working, you'll need to take the exact dose and exact number of pills in your regimen on time, every time. But there may be challenges waiting to trip you up, including:

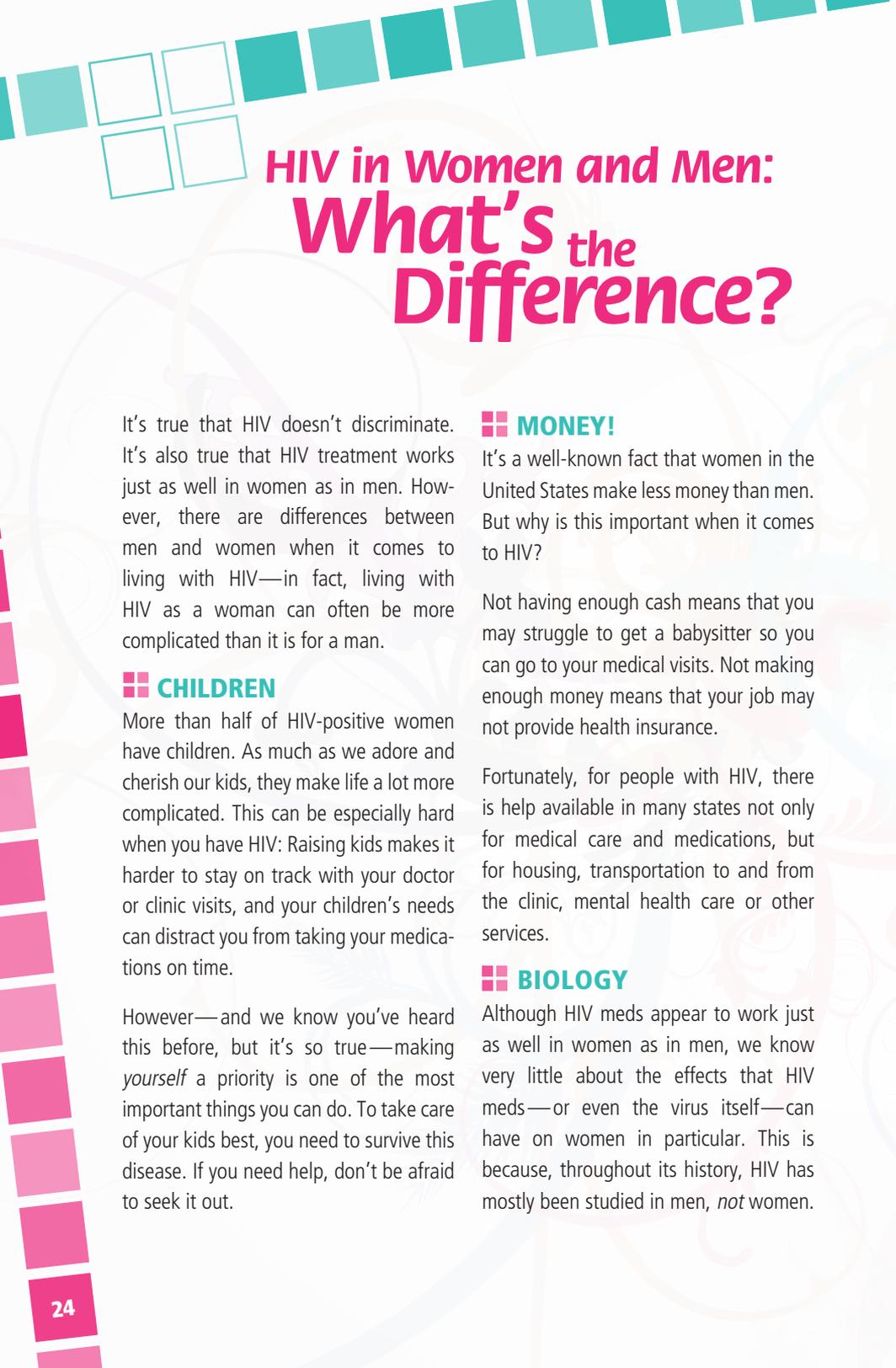
- Side effects
- Pregnancy
- Depression, drug addiction or other personal problems
- Forgetting to refill your prescription
- Illnesses or injuries
- Family emergencies or travel
- Getting tired of taking meds every day

Whatever the reason, and however hard it may be to talk about it, it's extremely important to bring up the problem with your HIV specialist or case manager before the problem interferes with your med schedule.

“For some people, HIV changes their lifestyle —now they feel healthier and are not abusing themselves anymore. That’s what happened to me.”

— Precious Jackson, diagnosed in 1998





HIV in Women and Men: What's ^{the} Difference?

It's true that HIV doesn't discriminate. It's also true that HIV treatment works just as well in women as in men. However, there are differences between men and women when it comes to living with HIV—in fact, living with HIV as a woman can often be more complicated than it is for a man.

❑❑ CHILDREN

More than half of HIV-positive women have children. As much as we adore and cherish our kids, they make life a lot more complicated. This can be especially hard when you have HIV: Raising kids makes it harder to stay on track with your doctor or clinic visits, and your children's needs can distract you from taking your medications on time.

However—and we know you've heard this before, but it's so true—making *yourself* a priority is one of the most important things you can do. To take care of your kids best, you need to survive this disease. If you need help, don't be afraid to seek it out.

❑❑ MONEY!

It's a well-known fact that women in the United States make less money than men. But why is this important when it comes to HIV?

Not having enough cash means that you may struggle to get a babysitter so you can go to your medical visits. Not making enough money means that your job may not provide health insurance.

Fortunately, for people with HIV, there is help available in many states not only for medical care and medications, but for housing, transportation to and from the clinic, mental health care or other services.

❑❑ BIOLOGY

Although HIV meds appear to work just as well in women as in men, we know very little about the effects that HIV meds—or even the virus itself—can have on women in particular. This is because, throughout its history, HIV has mostly been studied in men, *not* women.

“In my community in Baton Rouge, La., I’m probably the only minister who stands up, publicly and boldly, feeling beautiful and elegant, saying, ‘I’m not just HIV positive, but I’m living with AIDS. And this is what AIDS looks like.’”

— Bishop Joyce Turner Keller, Ph.D., diagnosed in 2001



This is slowly changing, but there’s still a huge amount we don’t know. For this reason, it’s extremely important to talk with your health care provider about any health problems you’re having, whether you’re on HIV meds or not. Don’t assume that your problem isn’t worth mentioning: It is.

■ ■ GYNECOLOGICAL PROBLEMS

Having HIV means that you’re more likely to develop gynecological problems. If you’ve just been diagnosed, make sure you get a complete gynecological evaluation. In addition, be sure to see a gynecologist experienced with HIV at least once a year. Make sure you’re checked for all sexually transmitted diseases, particularly HPV (human papillomavirus),

genital herpes and pelvic inflammatory disease.

MAKING YOURSELF A PRIORITY IS PROBABLY ONE OF THE MOST IMPORTANT THINGS YOU CAN DO TO LIVE AND THRIVE WITH HIV.

HIV-positive women may also experience early menopause. Talk to your health care provider if you experience any of these symptoms or if you’d just like to learn more about them.

Some other tips: If you ever have a vaginal yeast infection, be sure to treat it early to avoid complications. Also be sure to have a Pap smear every six months for the first year after your HIV diagnosis—and, if all is OK, once a year after that.

Remember that some women with HIV, especially those with a low CD4 count, experience irregular or long menstrual periods. Some

Gathering Strength From Others

Living with a life-threatening disease is no easy feat. It's especially difficult when you've got other problems. We asked a bunch of HIV-positive women to tell us some of the things that help them survive day to day.

Here's their advice.

MAKE LEMONADE OUT OF LEMONS!

"I try to use experiences that are painful or difficult to bring something good. My personal belief is that people with HIV who give up or are full of self-pity and anger, those people are perhaps harming themselves and don't even know it."

— Jane Fowler, 72, diagnosed in 1991



THINK LONG-TERM!



"When I first tested positive, I wish someone had told me that I was going to be OK and that I didn't need to feel ashamed because of my status. I wish someone had told me that I had a long life ahead of me. After finding out my status at 25 years old, I thought I was going to die by the time I was 30 and I spent my life savings thinking I was going to die. Nobody told me I would live this long! Eighteen years later and I'm still here."

— Trish Steen, 43, diagnosed in 1989

KEEP YOUR HEAD UP!

"HIV is not a punishment. Don't let it monopolize your life! It's very important that you learn to love yourself."

— Regina Brandon, 43, diagnosed in 1986



FIND DEVOTED FRIENDS!



"All the friends that I told, they all got emotional and started crying. But all of them, they said, 'No matter what, Raven, we will still love you and you will always be our friend.'"

— Raven Lopez, 17, diagnosed in 1991

GET A NEW PERSPECTIVE ON LIFE!

"Every day I wake up and realize that life is a gift. There's not a whole lot of time to be wasted. ... From a spiritual base, I believe the world is a good place and that the possibilities are endless."

— Loreen Willenberg, 54, diagnosed in 1992



BECOME FEARLESS!



"People had already done all the damage they could possibly do with their tongues and their fingers pointing. What else could they do to me? I became fearless ... I still have to go back to my faith in my God in heaven. He's the one who made me strong. He's the one who gave me the eyes to see what needed to be done."

— Desiree Herron, 50, diagnosed in 1996

FIND OTHER HIV-POSITIVE WOMEN!

"The first time I was in a room full of HIV-positive women, I was amazed. I felt like I was home. I thought: 'You're all living, you're all thriving, you're all fighting! You're all dynamic women! You're not monsters! You're real, great, vibrant, normal women. Wow! I can do this!' I stuck to them like glue."

— Shelley Singer, 49, diagnosed in 1997



STEP 10

Putting it All Together



“HIV is part of my life. I can’t get rid of it. I can’t turn the clock back. And I don’t know that I would, at this point. ... I balance the HIV with life, because the reality is, there is a lot more hope now for living a long life than we have ever had before. I’m thinking, oh, gosh, I have to plan for my retirement now. I never thought about that before. It was, like, why save for retirement? I won’t be here.”

— Cathy Olufs, diagnosed in 1995

In this booklet, we’ve talked about some of the most critical steps to take if you’ve been recently diagnosed with HIV: Educate yourself about HIV, find HIV support services and an HIV specialist, and prepare for and start HIV treatment if necessary. But perhaps the most important step you can take is the one that makes all the other steps possible: accepting your diagnosis and planning your future as a person living with HIV.

Regardless of the reason you were infected, something as life-changing as an HIV diagnosis usually gives people an unexpected chance to re-examine their lives. Many people with HIV say that their

diagnosis turned out to be an opportunity to better their lives. That may sound crazy to you right now, but having to face a serious health problem can motivate you to dig deep and make changes in your life that you may have been putting off, or that you never even realized you needed to make.

Some of these changes, of course, may be staring you in the face. If you drink too much or don’t exercise, it’s time to change that. If you smoke, it’s time to stop. Anything that adds stress, frustration or conflict—be it a bad relationship, a soul-crushing job or trouble paying the bills—can be a drag on your immune

"I think you find your strength from within. I think you have to go through your own little grieving process first, at least I did. Once you get used to that idea, you'll say, 'OK, I'm not going to be ashamed I have HIV.'"

— Bernie, diagnosed in 2006



system, or can make it harder for you to commit to taking your HIV medications on time, every time.

Talk to your HIV specialist, a counselor or a support group about these issues, and ask yourself what you can do to improve the situation. Never underestimate the impact that emotional health can have on your physical health.

You may have to do a lot of work and seek out emotional and maybe spiritual support, before you can educate friends and family about the realities of HIV, and help them separate the facts from the myths.

But know that isolation and silence are hazardous to your health. If you don't feel comfortable going to an HIV/AIDS organization for support, the Internet may be a lifesaver. There are an assortment of Web sites where you can learn more about HIV and its treatment, stay on top of the latest HIV news and even meet people. Want to

connect with any of the women featured in this booklet? All their stories and e-mail addresses are featured at www.thebody.com/women. But it's up to you to get out there. Once you connect with others, you'll be surprised at how invaluable you'll find the emotional support.

REACH
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Fortunata Kasege, who was diagnosed in 1997, says that after her diagnosis, "I had days when I would just stay home and cry all day. This changed after I went to my first support group. There I found a group of women who had lived with this disease for 10, 20 years. I was just amazed how healthy they looked."

Don't forget that there are more than one million HIV-positive people in the United States—many in the same position as you. Reach out for that support; it will strengthen you and challenge you to keep going, keep growing and keep living life to the fullest.