

POSITIVE?

how are you feeling?



a publication for HIV-positive women

a publication of

PROJECT
inform

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

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PROJECT INFORM

How are you feeling?

Though we live with our bodies every day, it's easy to lose touch with them, or not to feel or hear what they're telling us. Life can be so demanding, it's easy to forget how we're feeling. We have so much going on that we ignore our bodies' messages.

Yet, our feelings and body signals give us important clues about our overall health. Sometimes they're obvious, like when we get a cold. Other times they're subtle, like when we feel a little tired too often. The subtle signals are just as important as the obvious ones.

Recognizing and responding to body signals becomes even more important when you're living with HIV. They can be warning signs that something more serious is going on or is about to happen.

The purpose of this publication is to help you recognize feelings and signals that may be related to your HIV disease. It provides ideas about how to respond in ways that will make you *feel* better. This might mean getting more rest or eating better. It could mean going to the doctor or taking anti-HIV medications. So, before you can figure out what to do, really think about the question: *How are you feeling?*

Every HIV-positive woman should know some basic facts about HIV disease. There's plenty to learn, and lots of time to do it. But for starters, here are a few basics.

HIV infects certain cells in your immune system that play a key role in fighting infections. When you lose these cells, your immune system weakens and loses its ability to fight off infection and disease.

Stopping or slowing HIV from destroying immune cells is one goal of an anti-HIV strategy. To monitor HIV and your immune health, two simple blood tests are used. A viral load test tells you how much HIV is present and how fast it's reproducing in your bloodstream. The CD4+ cell (commonly called T cell) count gives you a rough measure of the strength of your immune system and the degree to which it has been damaged.

It's recommended that you get these tests taken regularly (every 3–6 months). If you see dramatic changes in the numbers or switch anti-HIV therapy, you may want to get these tests more frequently.

Viral load testing: Interpreting the results

Low viral load (generally below 10,000 copies/ml) indicates that HIV is reproducing slowly and the risk of HIV progression is low.

High viral load (above 100,000 copies/ml) indicates a higher level of viral activity and thus a higher risk for HIV disease progression.

Low, stable, or decreasing viral load level is considered a good thing. A high or increasing level demands attention and is often a major factor in deciding when to start or switch treatment.

Remember to consider CD4+ cell count.

Together, the test results more accurately indicate the risk for disease progression than viral load results alone.

CD4+ CELL COUNTS

CD4+ cell counts below 200 indicate a significant risk of getting *opportunistic infections* (OIs). These are infections that take advantage of the “opportunity” of a weakened immune system. When CD4+ cell counts fall below 50, there’s great risk of serious OIs. At this stage, CD4+ cell counts—rather than viral load tests—more reliably predict HIV disease progression.

It’s normal for tests to vary from one to another. So you should avoid panicking if you happen to see a number that seems abnormally high or low. Any time you get what looks like an alarming result, you should repeat the test for accuracy. Most doctors discourage people from changing therapy based on any single test result. Instead, it’s the change over time that should guide treatment decisions.

REMEMBER!

- Pay attention to trends, not just one test or absolute numbers.
- Never make a treatment decision based on one result—repeat the tests and confirm the numbers before starting, switching, or stopping therapy.

CD4+ cell count ranges	
OVER 500	“NORMAL” OR HIGH RANGE
BELOW 500	“PREDICTIVE” OR MEDIUM RANGE
	▶ Changes in CD4+ cell counts become “meaningful” and guide decisions around anti-HIV treatment.
BELOW 200	LOW RANGE
	▶ Increased risk for OIs. ▶ Consider treatment to prevent OIs

minding

your emotions

Often times, when asked how we feel, we immediately take stock of our bodies. Do I feel sick? Do I feel tired? Do I feel physical pain?

While these are important measures of how we feel, they're only part of the picture. How we feel emotionally is just as important as how we feel physically. In fact, our emotions impact our entire well-being.

Being diagnosed with HIV brings on many emotions, some difficult to deal with. After testing positive, many women feel afraid of getting sick or are concerned about how their partners, family, or friends will react. Many feel angry, depressed, or simply numb.

lots of women feel
HIV is the least
of their problems

It's important to acknowledge and express them. Sometimes that can be challenging, especially if no one knows about your HIV status.

At some stages, lots of women feel HIV is the least of their problems. No matter what the cause, these emotions can affect your physical and mental health. This is especially true when you bottle up or ignore your feelings. Or become paralyzed by them.

DEPRESSION

It's not uncommon for people to casually say they feel sad or down or depressed. Depression is something that most people experience. It can be a natural response to a situation, or it can be an illness in and of itself.



When depression becomes severe, it's like *life stops*. You may forget to take care of yourself as you normally would. Sometimes getting up in the morning becomes difficult or you forget to eat. If you have difficulty taking care of yourself, your health can suffer.

SIGNS OF depression

- Loss of interest in friends or normal activities
- Difficulty sleeping or sleeping too much
- Changes in eating habits
- Unintentional weight loss or abnormal weight gain
- Poor attention to grooming and bathing habits
- Loss of energy
- Frequent thoughts of death
- Loss of interest in being touched or having sex
- Prolonged unhappiness

Getting a grip on depression usually begins with communicating, like talking to a friend, joining a support group, or talking to a doctor or counselor. It may even start by writing about your thoughts and feelings in a journal. When depression is more severe or long lasting, a doctor may recommend certain medicines that can help.

The way we respond to other emotions like grief or anger can take similar shape. The important thing is to be aware of your emotions and make your emotional health just as much of a priority as your physical health.

When women are under stress they develop more infections, common colds, herpes outbreaks, and gynecological problems. Sometimes when we get stressed out we also get depressed, don't eat regularly, don't sleep well, or find it hard to take care of ourselves. All these things can affect our bodies, weaken our immune systems (our bodies' defense against infection and disease), and make us feel sick.

Finding ways to lessen stress, like those outlined in *Emotional Rescue* below, can actually help strengthen the immune system and keep you feeling better.

Emotional Rescue dealing with difficult emotions.

- Be with and do things with your friends.
- Talk to other people with HIV; chances are, others have felt the same way. Or consider a support group.
- Do things that make you happy, like take a bath, read a book, or listen to music.
- Do daily activities. Get up, bathe, get dressed, go out.
- Take a walk. Fresh air and exercise are good for the mind, body and soul.
- Record your thoughts and feelings in a journal.
- Stop or cut down on alcohol and drugs. They can cause depression and get in the way of addressing your emotions.
- Learn about HIV and local resources. This helps you realize you're not alone and can make you feel stronger!
- Talk to a doctor or counselor for help.

minding

your body

Usually, your body tries to tell you when something is wrong. Paying attention to what it's saying (or its symptoms) is the first step toward understanding the cause of what you're experiencing. Then, you can identify ways to deal with symptoms and their causes and try to prevent them from coming back.

Some of the most common symptoms and problems of HIV disease are connected. For instance, feeling tired and losing weight can reinforce each other. Are you losing weight because you feel extremely tired or are you tired because you're losing weight? Many symptoms can have the same cause, so once you find it they may all get better.

The next five pages explain these common conditions of HIV:

fatigue

weight loss

diarrhea

cough

anemia

nausea

headache

It's not unusual to feel fatigued or have low energy, especially when life is hectic. But sometimes, fatigue is a symptom of weight loss, depression, malnutrition, hormone imbalances, lack of exercise, HIV itself, or anemia.

If you're feeling more tired than usual, it's important to figure out why. Fatigue can create a vicious cycle—the longer you stay in bed, the harder it is to get up. Sometimes fighting fatigue may involve taking small steps to be in bed less and be active more. Other times, the cause of fatigue can be more important and need more attention, as in the case of anemia which is described on the next page.

Everyday problems or something serious?

- Weight loss, diarrhea, nausea, headache, cough—the list goes on. Some dismiss these as bothersome, everyday problems. Sometimes doctors do too. So even though they interfere with the day-to-day, it's easy to fall into a routine where you just grin and bear it.

It's important to get a handle on these conditions. If they persist or get worse, they could be signs of something more serious to come. They could also be side effects from your meds. Pay attention to these conditions. Monitor whether or not they get worse or happen frequently.

You don't have to feel bad all the time. Explore different ways to deal with problems like these. The first thing you try might not work, so don't be discouraged and certainly **don't give up!**

DIARRHEA

Diarrhea is a common problem, even more common in HIV disease. In people with HIV/AIDS, it can be caused by infections like parasites or bacteria in the gut. It can also be caused by HIV itself, or by side effects from anti-HIV medications.



Aside from being annoying, the biggest concern is that diarrhea can make you dehydrated and lose weight. If it occurs regularly (for more than a week) or it's accompanied by severe stomach pain or fever or your stools (poop) are black or bloody—or very pale and light—it's important to let your doctor know immediately. It could be a sign of something serious.

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Drinking lots of liquid like broth, water, or ginger ale when you have diarrhea helps prevent dehydration. Gatorade or Jell-O can also help. Avoid milk and fatty foods and try the “BRAT” diet (see *Nutritional Tips*, p. 12).

Any form of soluble fiber (foods that absorb liquid, like rice and oatmeal) can also be helpful.

Treating diarrhea without knowing its cause can do more harm than good. For example, diarrhea may be helping to eliminate an infection from your gut. In this case, taking medication to manage diarrhea may keep infections in your body longer. Anti-diarrhea medications like Lomotil, Lepectate, Immodium, or Pepto-Bismol can help ease diarrhea. So can bulking products like Metamucil. For more information on diarrhea, you can read Project Inform's publication, *Dealing with Drug Side Effects*.

WEIGHT LOSS

Weight loss can be a serious problem in HIV disease. Unfortunately, even though symptoms can be obvious it's not always seen as a problem. In fact, many positive women who lose weight because of problems due to HIV are praised and told they "look good".

Losing weight can be a bad thing. If you're losing weight, and it's not because you altered your diet or exercise patterns for that purpose, it's *never a good thing*. *If you experience this, you should definitely talk to your doctor.*

losing weight
can be a bad thing



Nausea, or feeling sick to your stomach, is common. Like diarrhea, it could be a drug side effect or indicate something else, like stress or an infection. Whatever the cause, it's not easy to live with. If nausea lasts more than two days, tell your doctor.

While vomiting often accompanies nausea (and vice versa), they're separate symptoms. If you experience one or both regularly, talk to your doctor. Anti-nausea drugs may help if you can't find other ways to bring it under control. For more information on nausea, read Project Inform's publication, *Coping with Nausea*, available through the National HIV/AIDS Treatment Hotline at 1-800-822-7422 and www.projectinform.org.

NAUSEA

ANEMIA

Anemia is low red blood cells. Those are the cells that deliver oxygen to different parts of your body. When your body is short on oxygen, you feel fatigued. Long-term or severe anemia can cause damage to your body.

Most people with HIV have anemia at some point. HIV causes it. So do many drugs used to treat HIV and hepatitis C. Lack of iron, vitamin B-12, or folic acid can also cause anemia. Problems with your periods can cause anemia, or problems with your periods can be a symptom of anemia.

Severe anemia can be life-threatening, particularly during pregnancy.

However, even less severe anemia can feel just as bad so that getting out of bed can be a major chore.

NUTRITION AND other food tips

- Fish, meat, and poultry are high in iron and vitamin B-12, both of which lower risk of anemia.
- Spinach, asparagus, dark leafy greens, and lima beans are high in folic acid, another nutrient that lowers risk of anemia.
- Keep easy-to-prepare foods on hand for times you're too tired to cook.
- The BRAT Diet (Bananas, Rice, Applesauce, and Toast) helps with nausea and diarrhea.

It's important to recognize symptoms of anemia. Blood tests can tell if your fatigue is due to anemia; if so, there are treatments to correct it. To monitor things like anemia, see a doctor and have regular blood work done at least every three months, even if you're not using anti-HIV medication. Changes in daily diet and plenty of rest can ease symptoms of anemia and help you feel better.



HEADACHE

The most common cause of headache is tension, something most women have at some point!

Medications, including anti-HIV drugs, can also cause headaches.

Mostly, headaches are just a pain and can be eased by over-the-counter pain killers like aspirin. They can also be helped and prevented by reducing stress. (If you have hepatitis or signs of liver disease, talk to your doctor before using ibuprofen or the various brands of acetaminophen like Tylenol, as they can be hard on the liver.)

When headaches just don't go away or become severe, it may indicate a more serious problem. Headaches with a stiff neck and fever can be a sign of a dangerous infection. Those that cause weakness or slurred speech can indicate a brain attack (stroke) and should be discussed with a doctor immediately.

COUGH

We cough to get something out of our lungs that shouldn't be in there or that is blocking normal flow of air, like toxic material from smoking or mucous from a cold or other infections. For normal coughs, lots of water can help. Over-the-counter meds can also help, as can breathing in moist air by taking a long, steamy shower or using a vaporizer.

Along with these typical causes of cough, people with HIV are vulnerable to certain lung diseases, like *Pneumocystis carinii* pneumonia (PCP). The signs of PCP include a dry cough that does not produce mucous, accompanied by shortness of breath and fever. Other serious lung infections that involve coughs are tuberculosis and bacterial pneumonia.

Got a bad cough?

You should see a doctor if any of the following occurs:

- Persistent cough (10 days) and fever
- Cough plus shortness of breath
- Dry cough plus fever
- A fever with chest pain
- Green or reddish mucous

gynecological

problems

Gynecological (GYN) problems can occur in all women. They're also some of the most common complications experienced by women living with HIV. GYN problems can be more serious and difficult to treat in women with weak immune systems.

GYN problems range from irregular periods to vaginal yeast infections that just won't go away. More serious complications can include cancers or painful warts on the vagina, labia (vaginal lips), and anal area (around your butt hole).

regular exams are crucial,
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don't have symptoms

Many women do not experience symptoms related to GYN problems, and these problems can remain undetected. Left untreated, they can further weaken the immune system. Therefore, regular exams to detect problems are crucial, *even* when you're feeling well and *even* when you don't have symptoms. Detection and treatment are critical steps to prevent a GYN condition from getting out of control.

GYN SCREENING

for women with HIV

Pap smear

This screening test can save your life. It can find the earliest signs of cervical cancer. It's recommended that women get Pap tests done at least once every three years, starting about three years after they start to have sexual intercourse, but no later than age 21.

Women, especially those living with HIV, should talk with their doctors about when and how often they should get a Pap test done. Your doctor may recommend more regular tests based upon your health and risk factors.

The Pap smear checks for changes in the cells of your cervix. It may detect inflammation, abnormal cells, or cervical cancer.

Your doctor will use a special tool to swab a sample of cells from the cervix. The sample will be tested for abnormalities. The process may be uncomfortable but usually doesn't hurt.

Colposcopy

This test examines your vagina, vulva, and cervix with an instrument called a colposcope. This test can be uncomfortable though it generally isn't painful. Sometimes, due to how the cells look, your doctor may also choose to do a biopsy, which can be painful.

Biopsy

This test removes a small piece of the cervical tissue that will be tested for abnormal cells. This may sometimes accompany a colposcopy and can hurt.

DON'T FORGET YOUR BREASTS!

Three tests are used to screen for cancer.

Mammograms (breast x-rays) are recommended every 1–2 years for women over 40. **Clinical breast exams** done by a health expert are recommended every three years for women 20–39. **Breast self-exams** can be done regularly to check for changes in breast tissue. Report any changes to your health care provider.

KEEP TRACK OF YOUR BODY!

Track your periods, hemoglobin (red blood cell) count, body weight, viral load, and CD4+ cell counts.

FOR MORE INFORMATION ...

Read Project Inform's publication, "Gynecological Conditions and HIV/AIDS".

PROBLEM PERIODS

Changes in periods are common in all women, but they may be especially common in HIV-positive women with lower CD4+ cell counts. These changes may include irregular, heavier or lighter periods, painful periods, or the end of menstrual bleeding altogether.

Tracking your periods from month to month is a good idea. A tracking chart is enclosed. Let your doctor know if you have any changes in your periods. It's important to determine why your period has changed.

GYN problems?

HERE ARE SOME COMMON CLUES ...

- Unusual or smelly vaginal discharge
- Cramping
- Irregular periods
- Genital warts
- Pain and itching around the vagina
- Pain during sex
- Burning or pain when urinating

working

with your doctor

The best way to get quality health care is to work in partnership with your provider. And good communication is the key.

This can be challenging when doctors see many patients and keep to tight schedules. Still, no matter what kind of insurance you have (or don't have) and how little time you have to see a doctor, you have the right to quality care.

Many women have several providers including their primary care doctors, prenatal specialists, gynecologists, therapists, dentists, etc. For each, there are things you should expect *and* offer. Much of the responsibility rests on you, but it gets easier as they become part of your health care routine.



- Lack of money should never prevent you from getting the health care you need and deserve! If you can't find what you need, ask for help as there may be resources and options available.

Your doctor should ...

- Know about HIV
- Respect and listen to you
- Talk in a way you understand
- Answer questions respectfully
- Describe all your options
- Explain benefits and risks of tests and medications
- Offer referrals

You should ...

- Expect to be treated with respect
- Be willing to learn about HIV and helpful resources
- Listen actively and ask questions
- Prepare for appointments by writing down questions, in order of importance
- Write down answers
- Know your limits
- Keep your paperwork (you may need it later!)
- Keep a list of therapies you take and review them with your doctor at each visit.
- Keep a record, for your files, of therapies you've taken before and why you stopped taking them. Highlight the names of meds you stopped because of allergic reactions.
- Bring your tracking records (CD4+ cell count, viral load, weight, and menstrual cycle history) with you to your appointment and fill in new information.

living well,

staying healthy

Managing HIV disease is not just about anti-HIV drugs, viral load tests, and CD4+ cell counts. It's a large picture that includes many parts of life!

This booklet talks a lot about emotional and physical health. Spiritual and sexual health are important areas, too. So are the health of our families and communities.



For many women, there are other factors that can affect their quality of life and taking care of themselves. Factors such as alcohol, substance abuse and/or domestic violence are a reality that you may be dealing with. Whether you currently use, are in recovery, or live with a violent partner, all these situations can affect how you feel. It is important that you work with someone whom you trust to help you get what you need to remain healthy and safe.

In terms of making treatment decisions, Project Inform has information that can help keep you informed about new therapies and strategies to treat HIV and symptoms related to it. This is true regardless of your CD4+ cell count, viral load, and general health. We're here to help when you need us.

Remember, *you* can impact your own health. What you do today will make a difference tomorrow. What's most important is that you develop a strategy to manage HIV that feels good for you, fits your lifestyle, and is in line with your choices. There's only one right way to manage your HIV infection: ***Your way.***

RESOURCES

National Domestic Violence Hotline

1-800-799-7233

Project Inform National HIV/AIDS Treatment Hotline

1-800-822-7422

W.O.R.L.D.

1-510-986-0340

Women Alive

1-800-554-4876

www.wellproject.org

www.aidsmeds.com

www.thebody.com

PROJECT INFORM PUBLICATIONS

Anti-HIV Therapy Strategies

Building a Cooperative Doctor/Patient Relationship

Coping with Nausea

Day One: After You've Tested Positive

Dealing with Drug Side Effects

Gynecological Conditions and HIV/AIDS ♀

Pregnancy and HIV ♀

Vaginal Candidiasis ♀

Strategies for When to Start Anti-HIV Therapy

(♀ women-specific)

TO RECEIVE INFORMATION

All of our material is provided free of charge.

To receive any of these publications or other available material, call our toll-free National HIV/AIDS Treatment Hotline at **1-800-822-7422**.

Or visit our website at www.projectinform.org.

Use the space below for important appointments, support groups, phone numbers, etc.

a publication of

PROJECT
inform
Information,
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Living With HIV/AIDS

In 1985, a group of concerned community members joined together to start a short-term “project” at a time when reliable information about HIV/AIDS and its treatment was nearly impossible to obtain. Since then Project Inform has worked to accelerate and facilitate advances in treatment, recognizing that therapeutic breakthroughs are only effective if people living with HIV have access to them. The hope this philosophy inspires is the core of Project Inform’s integrated approach to treatment education and advocacy.

Looking ahead, Project Inform will continue to serve as a trusted ally and a beacon of hope for the tens of thousands of individuals affected by HIV/AIDS who rely on us for information about optimal treatment strategies, advocacy to expand access to treatment and care, and our commitment to move the research agenda forward in the quest for better treatments and, ultimately, a cure.

To donate, to volunteer, or to receive more information about how you can support Project Inform, please call 415-558-8669. You can also visit us online at www.projectinform.org or email us at web@projectinform.org.

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