

Girl... Have You Heard?



Remember! Decide to act. Decide to live your best life!

Guided by the leadership and voices of women living with — and impacted by — HIV and AIDS, the mission of the Women's Institute at Gay Men's Health Crisis (GMHC) is to develop, promote, model, and share HIV/AIDS prevention and service programs that reach and support women, and are effective and accessible.

GMHC is a not-for-profit, volunteer-supported, and community-based organization committed to national leadership in the fight against AIDS.

Our mission: GMHC fights to end the AIDS epidemic and uplift the lives of all affected.

Gay Men's Health Crisis	HIV/AIDS Hotline	Web site
The Tisch Building 119 West 24th Street New York, NY 10011	1-800-243-7692 IN NYC: 212-807-6655 hotline@gmhc.org	www.gmhc.org

Women's Institute
212-367-1365

Acknowledgements

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This pamphlet is dedicated to GMHC's female clients and program participants whose resiliency and strength is an inspiration to us all.



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Ten Tips *for*
African-American
Women
Newly Diagnosed
***with* HIV**





Though it may feel overwhelming to be diagnosed with HIV infection, there are actions you can take to help you continue leading a full and healthy life. Here are some tips for living with HIV that you can take in a little at a time. You don't even have to read this brochure all at once! Also, keep in mind that though the following tips are ordered 1 through 10, most likely you will be doing more than one at a time and not necessarily in any order. Don't worry about that.

Consider these tips a guide to help you get started, or continue, on the road to living the best life you can with HIV infection.

1 DECIDE TO ACT

Sometimes when we are given bad news — whether expected or totally by surprise — the first reaction is to do nothing, especially when that news is as overwhelming as being told that “You have HIV infection.” It is so easy to put off thinking about it all until tomorrow. While it is definitely okay to take time to breathe and get your bearings, this is not the time to hide out.

By getting medical care and seeking out supportive services, you can live a productive life with HIV infection. But it is up to you to take the first step.

Decide to act. Decide to live your best life.

2 LEAN ON ME

You are pretty fierce, but you don't have to do this alone. Everyone needs someone to lean on once in a while. Don't be too afraid or too stubborn to ask for help when you need it. Just as HIV infection can challenge you in many ways, emotional support can come from different people and sources:

- Support groups
- Therapy or counseling
- Friends
- Family
- Case managers/social workers
- Religious or spiritual groups
- Health care providers
- Support programs for substance or alcohol use
- Community meal programs

Don't be fooled into thinking that just because you may not be in need of income support services, you don't need emotional support services. By allowing yourself support in whatever way is needed, you are truly showing your strength. Resources for support services include the following:

GMHC—Women's Care, Prevention & Support Services
(New York, NY) 212-367-1365; www.gmhc.org

ACE Program (Bedford Hills Correctional Facility)
(Bedford Hills, NY) 914-241-3100

African Services Committee (New York, NY)
212-222-3882; www.africanservices.org

BABES Network (Seattle, WA)
206-720-5566 or 1-888-292-1912 (Toll-free);
www.babesnetwork.org; E-mail: the_staff@babesnetwork.org

Blacks Educating Blacks About Sexual Health Issues
(BEBASHI) (Philadelphia, PA)
215-769-3561; www.bebashi.org

Chicago Women's AIDS Project (CWAP)
773-271-2242 or 773-995-8709;
www.chicagowomenaidsproject.org

Life Force: Women Fighting AIDS, Inc.
(Brooklyn, NY)

718-797-0937; www.lifeforceinc.org;
E-mail: info@lifeforceinc.org

The Well Project (Atlanta, GA)

404-474-3152; www.thewellproject.org;
E-mail: info@thewellproject.org

Women Alive (Los Angeles, CA)

1-800-554-4876 or 323-965-1564
www.women-alive.org; E-mail: info@women-alive.org

Women Organized to Respond to Life-threatening Disease (WORLD) (Oakland, CA)

510-986-0340; www.womenhiv.org

Women's HIV Collaborative of New York (New York, NY)
212-367-1012; www.womenscollaborative.com



3 FIND A DOCTOR THAT'S RIGHT FOR YOU

When you have HIV infection you need the best doctor you can get. Research suggests that having a good relationship and communication with your doctor should facilitate better medical decision-making and adherence to medication.

Sometimes you may find everything you need in 1 doctor. Sometimes you may need both a primary care doctor and an HIV specialist. And sometimes you may decide that the doctor you found is not right for you and you want to find a new one. All of this may also depend on your health insurance. Plus, make sure you don't forget about your other non-HIV health issues. African-Americans have higher rates of some diseases than others. Other health conditions can be serious and could make managing your HIV infection harder.

Finally, be honest and frank about sexual issues, including pregnancy or the desire to become pregnant, with your gynecologist and your primary care doctor without embarrassment. Speak up; don't wait for your doctor to mention the topic.

Finding a doctor requires shopping around. Ask yourself the following questions:

- What kind of patient am I? For example, do I need a full partnership with my doctor? Or can I rely on my doctor to drive the decision-making with my input?
- Would I prefer a female or male doctor?
- Do I require special office hours because of my work or household obligations?
- Is there a hospital to which I would not want to be admitted?
- Would my doctor be able to see me if I were hospitalized?
- What do my friends think about their doctors? Ask them what they like and dislike.

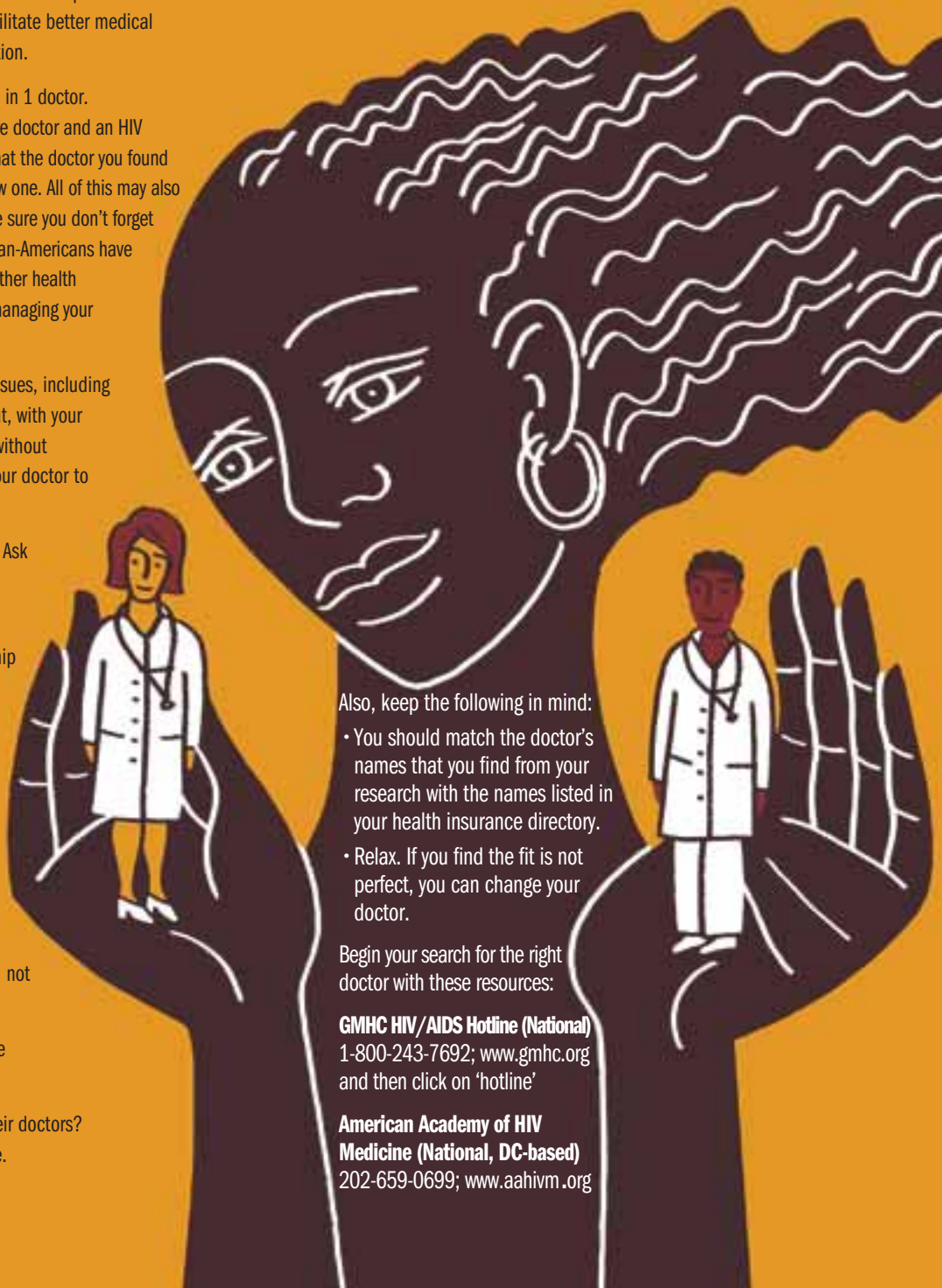
Also, keep the following in mind:

- You should match the doctor's names that you find from your research with the names listed in your health insurance directory.
- Relax. If you find the fit is not perfect, you can change your doctor.

Begin your search for the right doctor with these resources:

GMHC HIV/AIDS Hotline (National)
1-800-243-7692; www.gmhc.org
and then click on 'hotline'

**American Academy of HIV
Medicine (National, DC-based)**
202-659-0699; www.aahivm.org



4 KNOW YOUR NUMBERS

Always get a copy of all laboratory results and bring them with you to each doctor's visit. Only after a thorough physical exam and laboratory tests can your doctor tell you if it is medically necessary for you to take HIV medications. Only you, with your doctor's help, can decide if you are emotionally ready to take HIV medications. There is support available to assist you in preparing to take HIV medications (also known as "meds") and that will provide ongoing support when you start.

The first step in making treatment decisions is to know what you are working with. The main numbers you will hear about are your T-cell count (a marker of your immune system health) and your viral load (a marker of how HIV is reproducing in your blood). Also, laboratory results reveal everything from the amount of sugar (glucose) in your blood, to how well your liver is working, to whether you still have your childhood antibodies, or the antibodies for hepatitis A, B, or C.

You might want to consider talking to your doctor about joining a clinical research study that's right for you. You might benefit from access to new treatment regimens. For one thing, there are not enough women in currently available studies. This needs to change if women are going to get information on how HIV and the medications used to treat it affect women's bodies differently than men's.

Look here for some resources for HIV treatment information including clinical studies:

AIDS Community Research Initiative of America (ACRIA) (National)

212-924-3934; www.acria.org

The Well Project (Atlanta, GA)

404-474-3152; www.thewellproject.org;

E-mail: info@thewellproject.org

www.clinicaltrials.gov



5 LEARN ABOUT YOUR BENEFITS

What's in your health insurance policy? Do you know if there are any limits on medical services and pharmacy use? If you are working, what is in your short-term or long-term disability insurance policy? Can your life insurance policy be turned in for cash? What if you do not have any health insurance to begin with? What if you are homeless?

There are many benefits that are available to HIV-positive people. You do not need to become an instant expert on the details of each program listed here. That would be too much effort for anyone right now. The point is: There is assistance available for you.

Check with your local HIV or AIDS service organization for help applying for these and other benefits as benefits differ from state-to-state.

Here are some of the most common benefits:

ADAP and ADAP Plus (AIDS Drug Assistance Program) – These are state run HIV-drug assistance programs. They also help pay for doctors, labs, and private insurance premiums. ADAP is not comprehensive. It does not cover hospitalization or non-HIV related medical care.

Medicaid – Medicaid provides a core set of benefits, which may vary by state. Medicaid is a federal insurance and long-term care program, but individual states share the cost and have the option to provide particular benefits. In New York State, for example, Medicaid is a medical program associated with public assistance or SSI to help those who cannot pay for medical care.

Medicare – Medicare is a national health insurance program for those who have been on SSD for 2 years, or who are turning 65, or who have end-stage renal disease or ALS. It pays 80% of hospitalization, doctors', and lab bills. Medicare can work in conjunction with Medicaid, ADAP, and private insurance.

Public Assistance (PA) – Also known as Welfare, Public Assistance provides cash assistance and Food Stamps to people who have limited or no income and resources.

Section 8 – Section 8 is a federal housing assistance program.

Social Security Disability Insurance (SSD) – SSD is the federal insurance program run by the Social Security Administration (SSA) for disabled people who have worked “on the books” and paid FICA taxes for more than 10 years or 40 quarters. The amount of the monthly benefit depends on your work history.

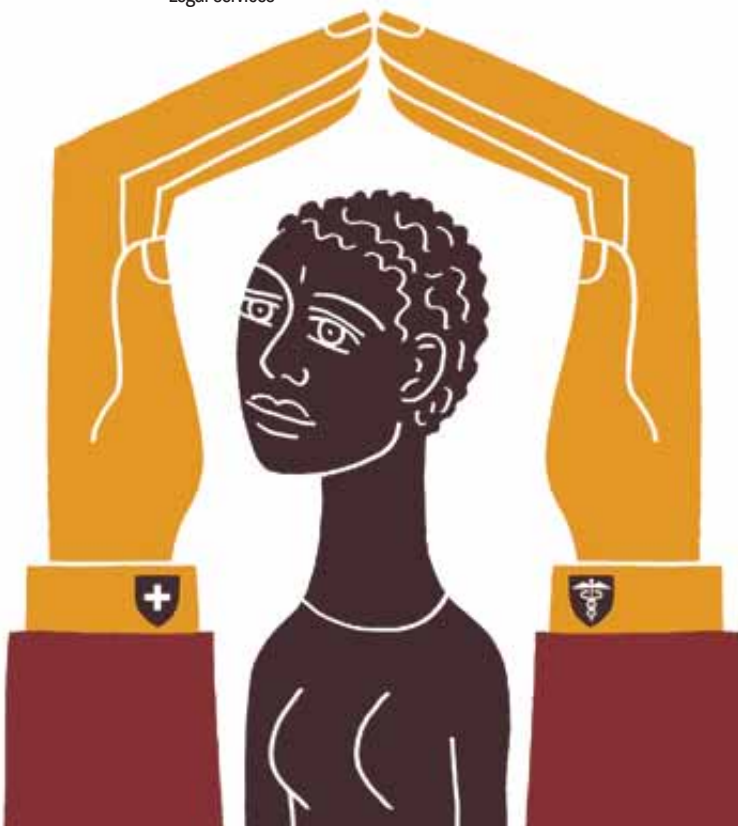
Supplemental Security Income (SSI) – SSI is a federal program, run by the SSA pays a monthly benefit for people who are disabled and did not work enough to be eligible for SSD, or did not work at all and have limited income and resources.

Short-Term and Long-Term Disability – These benefits are usually associated with employment and can be organized through your employer.

HIV/AIDS Services Administration (HASA) – Localities may provide supplemental support to people living with AIDS. For example, any person living in the city of New York who has, or has ever had, AIDS or certain HIV symptoms as defined by the New York State AIDS Institute (list available through GMHC Advocacy Helpline) is eligible for services through HASA. These services may include benefits such as enhanced nutritional supplements, transportation, and rent allowances from PA. HASA also provides housing assistance to those who are homeless or potentially homeless. Please contact your local health or human services department to find out if such a program exists in your city, town, or county.

Plus, you may also find additional services helpful in managing or obtaining the appropriate benefits for you. They include:

- Case management services
- Home health services
- Legal services



6 PUT YOURSELF FIRST

We tend to put the well-being of other people before our own health. As women, we feel this is expected of us. Not so sisters! If we took better care of ourselves, we'd be more able to care for those around us. Besides, staying healthy with any chronic illness requires a certain degree of discipline and self-care.

Some activities to get you started include:

- Exercise the power of “No” more often.
- Fit your doctor’s appointments into your schedule.
- If you are taking HIV medications (or other kinds), design a regimen with your doctor that you can easily follow and which fits into your life.
- Keep your benefit appointments; being able to meet your financial/other needs is a part of self-care, too.
- Take time out to eat the best quality food you can afford.
- Get a little exercise each day.
- Get a massage or have an acupuncture treatment.
- If you smoke, consider getting help to quit.
- If you currently use substances, consider getting help.
- Do something that feeds your soul, like take some quiet time, read, meditate, or just listen to music each day.
- Save the drama in your life for nightly TV.

Be sure to contact your local HIV/AIDS service organization that provide services to women as they often offer retreats and other support services for women:

**GMHC–Women’s Care, Prevention & Support Services
(New York, NY)**

212-367-1365; www.gmhc.org

BABES Network (Seattle, WA)

206-720-5566 or 1-888-292-1912 (Toll-free);
www.babesnetwork.org; E-mail: the_staff@babesnetwork.org

Chicago Women’s AIDS Project (CWAP)

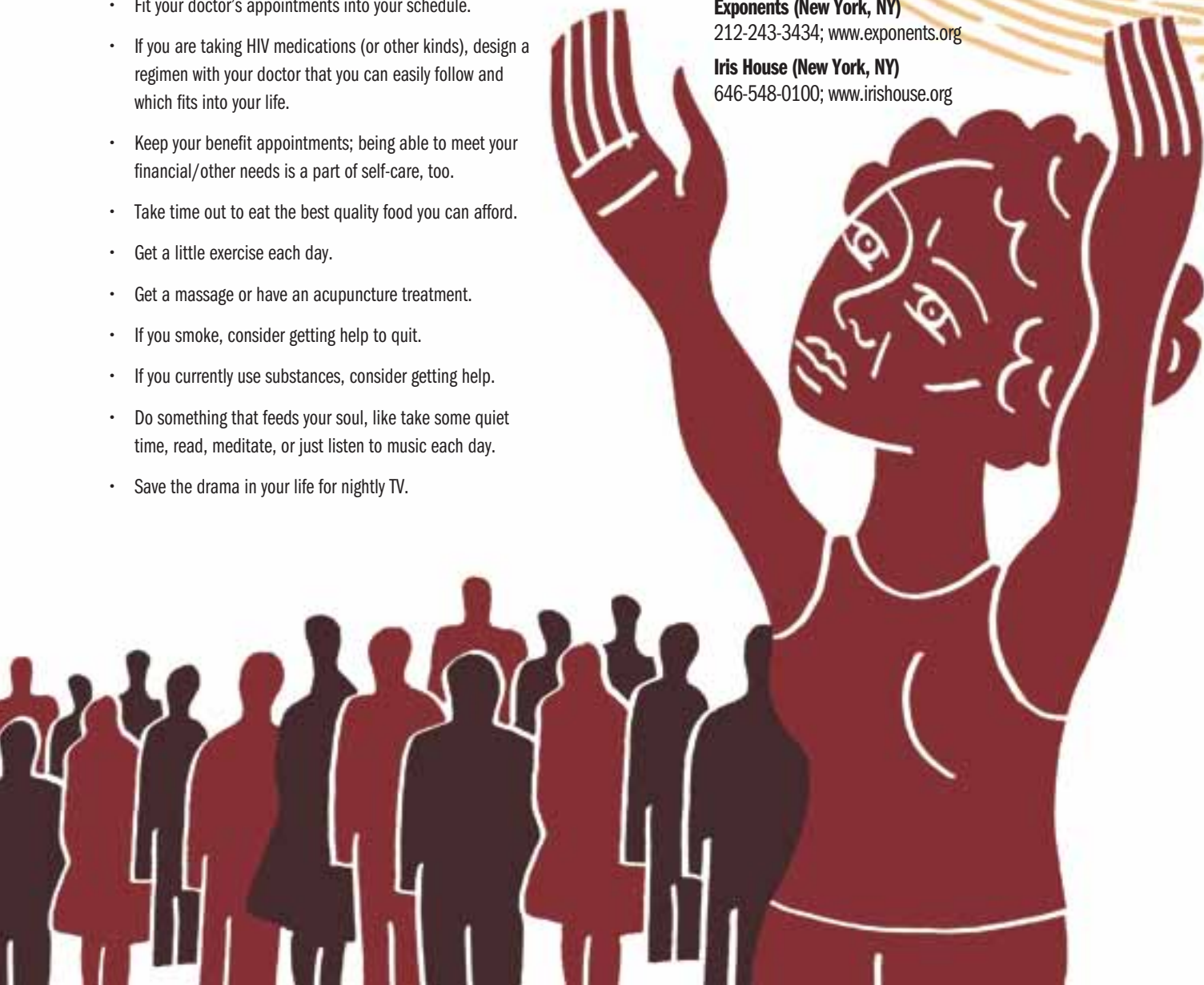
773-271-2242 or 773-995-8709; www.chicagowomenaidsproject.org

Exponents (New York, NY)

212-243-3434; www.exponents.org

Iris House (New York, NY)

646-548-0100; www.irishouse.org

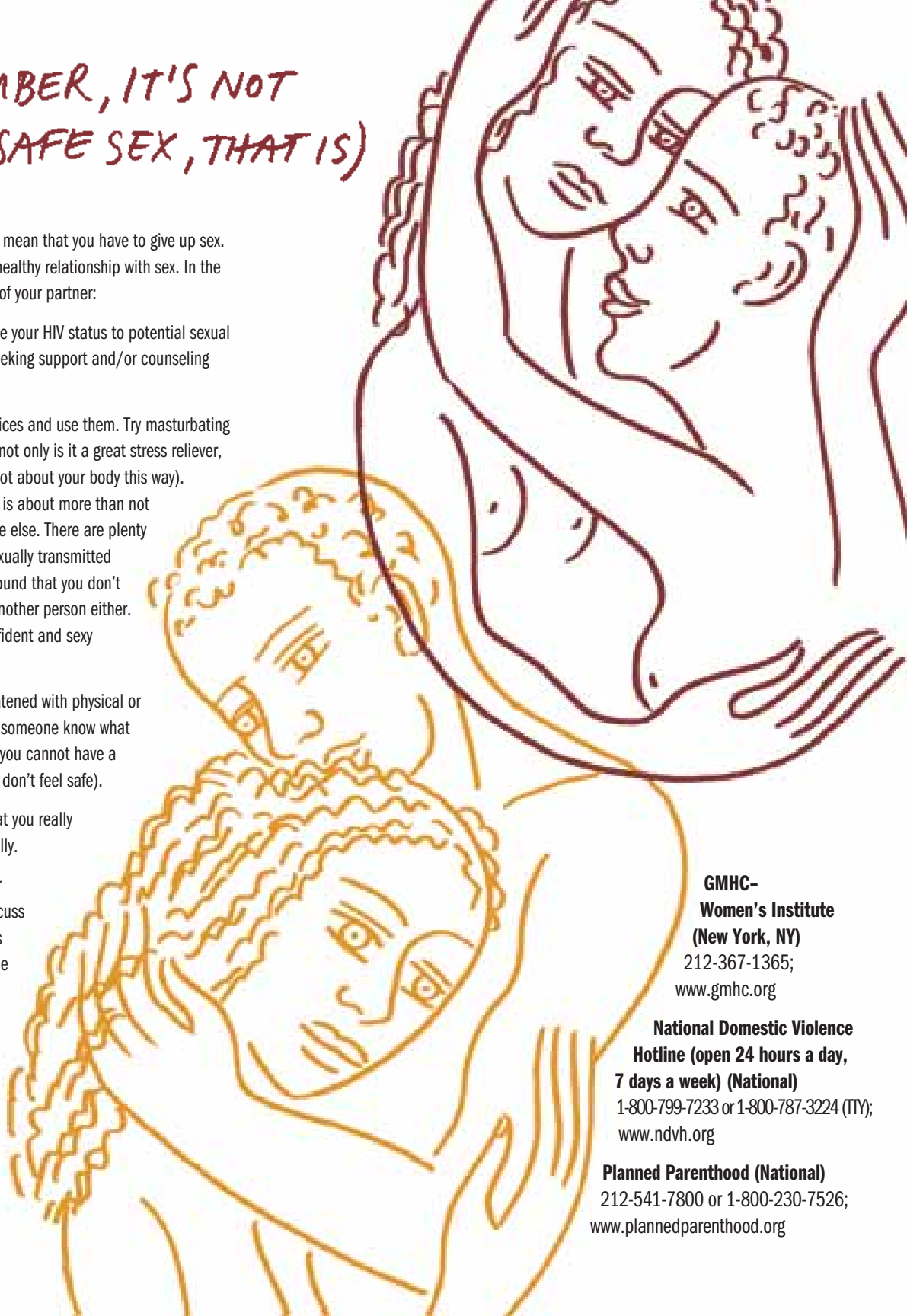


7 REMEMBER, IT'S NOT OVER (SAFE SEX, THAT IS)

Having HIV infection does not mean that you have to give up sex. In fact, now is the time for a healthy relationship with sex. In the interest of self-care and care of your partner:

- Remember to disclose your HIV status to potential sexual partners (consider seeking support and/or counseling before doing so).
- Learn safer sex practices and use them. Try masturbating with or without toys (not only is it a great stress reliever, but you also learn a lot about your body this way). Remember, safer sex is about more than not passing HIV to anyone else. There are plenty of other diseases (sexually transmitted diseases or STDs) around that you don't want to catch from another person either. Then you can be confident and sexy without worry.
- If you are being threatened with physical or emotional abuse, let someone know what is happening to you (you cannot have a healthy sex life if you don't feel safe).
- Get in touch with what you really want and need sexually.

Women's support groups offer excellent opportunities to discuss sexual and relationship issues (face it – you can't divorce the body from the brain).



**GMHC–
Women's Institute
(New York, NY)**
212-367-1365;
www.gmhc.org

**National Domestic Violence
Hotline (open 24 hours a day,
7 days a week) (National)**
1-800-799-7233 or 1-800-787-3224 (TTY);
www.ndvh.org

Planned Parenthood (National)
212-541-7800 or 1-800-230-7526;
www.plannedparenthood.org

Sometimes in order to get what you need, you have got to let someone know what is going on with you. But not everyone needs to know your HIV status.

Though there are no hard rules when it comes to disclosing your HIV status, consider the following before telling:

- Who are you telling (sexual partner, parent, minor or adult children, and/or medical provider)?
- Why are you telling (for example, are you sick)?
- Be prepared for different reactions (positive, hesitant, or negative).
- Have supportive resources available (pamphlets, Web sites, seminars, or support groups) for those to whom you are disclosing.
- When you do decide to disclose your HIV status to a past or present sexual partner, make sure you are safe from a violent reaction (consider asking assistance from a doctor, social worker, case manager, or other person).
- Before disclosing to an employer, consider consulting an attorney to protect your rights
- There is no right time. The best time is when you are ready.

There is support available for when you are ready to disclose your status. Start with these resources:

GMHC—Women’s Care, Prevention & Support Services (New York, NY)

212-367-1358; www.gmhc.org

African Services Committee (New York, NY)

212-222-3882; www.africanservices.org

Chicago Women’s AIDS Project (CWAP) (Chicago, IL)

773-271-2242 or 773-995-8709;
www.chicagowomenaidsproject.org

HIV Law Project (New York, NY)

212-577-3001; www.hivlawproject.org

Minority AIDS Project (Los Angeles, CA)

323-936-4949; www.map-usa.org

New York State Department of Health (New York, NY)

1-800-541-2437; www.health.state.ny.us

NO/AIDS Task Force (New Orleans, LA)

504-821-2601; www.noaidstaskforce.org

SisterLove, Inc. (Atlanta, GA)

404-505-7777; www.sisterlove.org

Southside Health Association Luck Care Center (Chicago, IL)

773-233-5850; www.luckcarecenter.org

The Well Project (Atlanta, GA)

404-474-3152; www.thewellproject.org;
E-mail: info@thewellproject.org



8
DECIDE
WHO
TO TELL AND
WHEN



9 TAKE CARE OF YOUR LEGAL BUSINESS

Unfortunately, having HIV can sometimes present challenges that must be addressed in the legal system. It is also important to get the rest of your personal affairs in order. Some of the legal issues that might arise around HIV include:

- Wills, Powers of Attorney for both health care and your estate, and Advance Health Care Directives
- Future care, child custody, and other family issues
- Debts
- Prison or probation Issues
- Immigration
- Housing, employment, or other areas of discrimination

These are all issues that can prevent you from living the quality life you deserve and can, in a lot of cases, be made better with legal assistance. Legal resources are available for people at all income levels. For more information call one of the following resources:

GMHC—Legal Services (New York, NY)

212-367-1040; www.gmhc.org

AIDS Project Los Angeles (Los Angeles, CA)

213-201-1600; www.apla.org

AIDS Legal Council of Chicago (Chicago, IL)

312-427-8990; www.aidslegal.com

African Services Committee (New York, NY)

212-222-3882; www.africanservices.org

American Civil Liberties Union AIDS Project (National, NY-based)

212-607-3300; www.aclu.org/hiv

South Brooklyn Legal Services (Brooklyn, NY)

718-237-5546; www.sblls.org

HIV Law Project (New York, NY)

212-577-3001; www.hivlawproject.org

Legal Action Center

(New York, NY)

212-243-1313; www.lac.org



I wish to

TO BE THE CONDUCTOR OF YOUR LIFE

You know the old saying: “Nobody cares as much about you as you”? It may be twice as true if you have HIV infection. Meaning, there is so much to keep up with when you have HIV, that no one agency or person can do it all for you. You have to be the conductor of your life. It is up to you to ask the hard questions, demand answers, and keep tabs on how the search for the services you need is progressing.

Create a filing system that you’re comfortable with and keep up with all the paper work. It doesn’t have to be fancy or expensive. You can keep your papers in an old shopping bag, but just be sure to keep close tabs on all of your important paperwork. For example: Your case manager or advocate may file the disability application for you, but you may need to follow up.

The following may help keep you on track:

- Always make copies of any application or document you submit.
- Bring a list of questions for the doctor each visit so that you are more likely to get your most pressing issues taken care of.
- Begin to make a habit of taking down the name and title of anyone who gives you official information.
- Help your doctor/case manager/advocate help you – give complete and accurate information and follow through on assigned tasks.
- Get a trusted friend or family member to help you out if this sounds like a lot of work.

Many HIV/AIDS service organizations offer classes, resources, or opportunities for different advocacy topics. Check out these organizations or call your local HIV and AIDS service organization:

**GMHC–Women’s Care, Prevention & Support Services
(New York, NY)**

212-367-1365; www.gmhc.org

**AIDS Community Research Initiative of America (ACRIA)
(National)**

212-924-3934; www.acria.org

Black AIDS Institute (National, CA-based)

213-353-3610; www.blackaids.org

**Blacks Educating Blacks About Sexual Health Issues
(BEBASHI) (Philadelphia, PA)**

215-769-3561; www.bebashi.org

Chicago Women’s AIDS Project (CWAP)

773-271-2242 or 773-995-8709;

www.chicagowomenaidsproject.org

Community Education Group (National, DC-based)

202-543-2376; www.communityeducationgroup.org

Exponents (New York, NY)

212-243-3434; www.exponents.org

Housing Works (Brooklyn, NY)

347-473-7400; www.housingworks.org

Minority AIDS Project (Los Angeles, CA)

323-936-4949; www.map-usa.org

NO/AIDS Task Force (New Orleans, LA)

504-821-2601; www.noaidstaskforce.org

SisterLove, Inc. (Atlanta, GA)

404-505-7777; www.sisterlove.org

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The Well Project (Atlanta, GA)

404-474-3152; www.thewellproject.org

Women Alive (Los Angeles, CA)

1-800-554-4876 or 323-965-1564;

www.women-alive.org

**Women Organized to Respond
to Life Threatening Diseases
(WORLD) (Oakland, CA)**

510-986-0340; www.womenhiv.org



