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- + TREATMENT INFO AND NUTRITION TIPS FOR HIV+ WOMEN
- + 30 (CHEAP AND FUN!) WAYS TO TAKE CARE OF YOURSELF
- + HOW TO FIND YOUR INNER GODDESS
- + MAMA MIA! PREGNANCY AND PARENTING
- + BEATING THE BLUES

*Sisters we Doin' it  
for Themselves!*

# *the* Positive Side

HOLISTIC HEALTH INFORMATION & VIEWS



Canadian AIDS Treatment  
Information Exchange

Réseau canadien  
d'info-traitements sida

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*"The thing that women have got to learn  
is that nobody gives you power.  
You just take it."*

– Roseanne Barr

These words, from the loudmouthed matriarch of TV's premier dysfunctional sitcom family, struck a chord with me when I first read them years ago and were a refrain in my mind during the production of this special women's issue of *The Positive Side*. "Taking power" is easier said than done, as we all know. How to do this when the odds are stacked against you...as a woman, person living with HIV/AIDS, drug user, single mother, gay man or lesbian?

One of the oldest slogans of AIDS activism is "knowledge = power." That conviction is the driving force of the work we do here at CATIE: disseminating cutting-edge treatment information so people with HIV/AIDS (PHAs) have the knowledge they need to make informed decisions about their health care and quality of life. Along with that knowledge often comes a sense of empowerment. As Jane Strickland, who's been living with HIV for 13 years, says in these pages, "The more you know, the more empowered you can become."



Photographer Jake Peters sets up the cover shot at Loftus Lloyd Café.

Knowledge comes in many shapes and sizes. There's treatment knowledge – knowing the facts and keeping up to date on the latest research. And then there's the deeper knowledge about living with HIV – the emotional, sharing, communal and inspirational stuff that lets you know you're not alone as you face the challenges of life with HIV. This double issue is jam-packed with both kinds of knowledge – all the info a woman needs to reach her potential in the health and happiness department – to help make it the useful reference guide we wanted to create for women, with women.



HIV infection rates are on the rise in women. Before 1995, women represented 8% of new HIV infections in Canada. In 2001, the number rose to 25%. Globally, 50% of adult PHAs are now women. AIDS disproportionately affects women and girls who are vulnerable and who shoulder the burden of caring for others. The executive director of the United Nations Development Fund for Women (UNIFEM), Noeleen Heyzer, recently said: "We must do all we can to loosen and remove the grip of this terrible disease. I believe that one of the most powerful HIV vaccines available today is women's empowerment... Women's empowerment is the key to reversing the epidemic." As you'll see from reading this *Positive Side*, it doesn't take the head of UNIFEM to know this.

Gracing the cover are women who live with HIV/AIDS and those who work with HIV+ women (including Shamim ShambeMiradam, a CATIE staff member who's been working with HIV+ women for the past decade). I want to thank them all for taking time out from their busy lives to make this *Positive Side* so vivacious. Their stories, experiences and feelings – and those of many more HIV+ women (most of whom live too far to have made it to the photo shoot) – infuse this issue. We posed the following question to each woman we interviewed: "What subject is nearest and dearest to your heart as a woman living with HIV?"

Their responses are a revelation. Revel in them! They are sure to inspire. Share the magazine with your HIV+ sisters...and brothers (there's stuff for you too!). Take it to your doctor, nurse or other health care provider, because they learn from you as well. Read it on the bus and let people glance over your shoulder and learn a thing or two about the fabulous, gutsy women who live with HIV.

**ROAR.**

*RonniLyn*



"Girls" just wanna have fun!



The cover women strike a pose.

**Jocelyn Paul, 49**

Diagnosed with full-blown AIDS: 2000 (with 3 CD4 cells); CD4 count: 117; Viral load: undetectable. Volunteer at AIDS New Brunswick and Healing Our Nation. St. Mary's First Nation, New Brunswick

I try to learn a lot about HIV and bring it back to my community. I recently spoke to some Aboriginal high school students about HIV. Our community is not in the woods somewhere, it's right in the middle of the city, so youth can get a hold of drugs and alcohol quite easily. They should know that HIV can happen to anyone. I never thought it would happen to me and I'm having a really hard time with it now.

Family and community support is very important. I get a lot of support from my kids, grandchildren and community. I'm open about my status and haven't faced any problems in my community yet, even though I know there are a lot of problems out there. If my community hadn't accepted me, I'd be dead by now. But they care; they ask me about the medications and whether they're working for me. Community acceptance makes such a big difference.

When I was diagnosed, I couldn't talk to anyone else, I had nobody to call. I could feel my spirit dying. Then I went on a women's retreat, where I met other HIV+ women. I got a lot of support from other PHAs. They became my family. Now everybody knows I have HIV. I've even asked AIDS New Brunswick to keep my name and number open to anyone who'd like to talk about HIV. I'd like to reach the women who have HIV and no one to talk to, who want to learn more. It's true, there are a lot of differences between Aboriginal PHAs and other PHAs, but we all have one disease. ♂



**Jane Strickland, 40+**

Diagnosed with HIV: 1990; CD4 count: above 300; Viral load: undetectable. Professional PHA (board member, committee member and advocate at Voices of Positive Women, HIV/AIDS Regional Services, Ontario AIDS Network, Canadian Treatment Action Council). Gananouque, Ontario

You don't have to do this alone. Having a strong support network helps you to live with the virus and break down the isolation. Women tend to feel isolated for many reasons. Women also have to look after everybody else. A lot of women don't have the resources that men do. With so many burdens and obligations, it's harder for us to ask for help.

Support is very important for me and over the years I've developed a strong support network. I have to express my high regard for the gay community, as they had to fight the hardest, and this is where 90% of my support comes from. Every time I find out that someone is newly diagnosed, I get them connected. It's vital to know that you don't have to do it alone; there is support out there. There is somebody out there who knows what you're talking about. ♂

## The Positive Side

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# Taking Care of Yourself

# 30

## NICE THINGS TO DO THAT COST (nearly) NOTHING

by Rebecca Denison

**1 Breathe.** When you get overwhelmed or anxious, stop and take three long, deep breaths. Notice how it can calm you.

**2 Refuse to be a victim.** Focus on what you *can* do, not on what you can't. Focus on *living* with HIV, not *dying* of AIDS. Say "I *have* HIV," not "I *am* HIV". Seek support, not pity.

**3 Listen to your mother.** Get plenty of sleep. (Try music or a meditation tape if you can't sleep.) Eat nutritious food. Take a daily multivitamin. Get fresh air.

**4 Call a toll-free hotline.**  
To talk with another woman with HIV:  
I in Ontario: Voices of Positive Women **1.800.263.0961**  
I in Quebec: CRISS (Centre de Ressources et d'Interventions en Santé et Sexualité) **1.866.240.0090**  
I in New Brunswick: AIDS New Brunswick **1.800.561.4009**  
I in BC: Positive Women's Network **1.866.692.3001**  
For HIV info:  
I Call your provincial or territorial HIV/AIDS hotline. Go to [www.cdnaids.ca](http://www.cdnaids.ca) and click on "contacts and links" to find the 1.800 number for you.  
I Call Health Canada's Division of HIV/AIDS at **613.952.5258** (not toll-free). Or go to Health Canada's Bureau of HIV/AIDS, STD and TB website at [www.hc-sc.gc.ca/pphb-dgspsp/hast-vsmt/index.html](http://www.hc-sc.gc.ca/pphb-dgspsp/hast-vsmt/index.html)  
For treatment info: call CATIE **1.800.263.1638** or go to [www.catie.ca](http://www.catie.ca)

**5 Educate yourself about HIV.** Subscribe to a newsletter (most are discreet and free for people who can't afford to pay). Go to an educational forum. Talk with a treatment advocate. Use the Internet. Go to the library. Avoid outdated information; treatment info changes quickly.

**6 Exercise.** It's good for your body and helps release stress. Don't worry about picking the "right" activity; do something you love so you're more likely to do it. Find an exercise buddy. Go for a walk. Ask around about yoga or Tai Chi classes.

**7 Express yourself; ask for support.** Talk with your friend. Hug your mom. Cuddle your kids. Cry with your sister. Share your feelings with your partner. Professional counsellors, therapists and clergy can also offer support.

**8 Embrace your own spirituality.** Spirituality means different things to different people. Some find inspiration in nature, others in meditation or chanting, and others in their synagogue or church. Many faith organizations now have AIDS ministries to support HIV+ people and their loved ones. If you feel angry at God, acknowledge it. HIV is a virus, not a punishment. You don't have to spend time with people who judge you or your disease.

**9 Ask for copies of your labs.** Learn what they mean.

**10 Think and act positively.** Seek out people who are honest, trustworthy and supportive. Give yourself permission to temporarily or permanently distance yourself from people who are abusive or who make you feel badly about yourself. Write what you would want your obituary to say; then take steps to become that person.

**11 Cry when you need to.** Let it out. Think of it as allowing negative emotions to flow out of you to make room for positive feelings to come in. Let someone hug you as you cry; they can't get HIV from your tears.

**12 Find safe outlets for your anger.** Talk it out or give yourself a "time out." Write letters you may or may not send. Vent with a trusted friend.

**13 Have fun!** Laugh at least once a day.

**14 Forgive yourself and others.** Try not to waste precious energy being angry, bitter, jealous or resentful. Forgive yourself for past mistakes. Don't blame yourself for having HIV. Most adults have put themselves at risk; some of us got infected, the others were lucky.

**15 Accept responsibility.** Pledge that HIV stops with you. Use condoms. Don't share needles.

**16 Talk to other HIV+ people.** It can be a relief to talk to people who know what you're going through. They can share how they disclosed, made treatment decisions or dealt with safer sex. Find them at AIDS organizations, support groups, retreats, educational forums, conferences or hotlines.

**17 Explore complementary therapies.** Vitamins, herbs and acupuncture are rarely free, but many people find them helpful to manage symptoms or side effects of medications. Talk with your doctor because some, like St. John's wort, can have interactions with HIV medications.

**18 Explore art for fun or therapy.** Play with clay, colour with your kids. Learn something new about yourself.

**19 Reduce use of drugs and alcohol.** If you or a loved one are using drugs or alcohol but want to stop, Alcoholics Anonymous (AA) and Narcotics Anonymous (NA) can help. If you inject drugs and can't or don't want to stop, ask if your community has a needle exchange.

**20 Pamper yourself.** Take a hot bath, with candles, scents and nice music. Do your nails. Wear something comfortable. Invite a friend over for a video and popcorn.

**21 Eat safely.** Avoid raw or undercooked meats/fish/eggs. Don't leave food out that should be refrigerated. Use separate cutting boards for raw meats and veggies. Don't take chances with spoiled food. "If in doubt, throw it out."

**22 Journal writing.** Write about how you're feeling or what you're learning. Don't worry about grammar or spelling. It's just for you.

**23 Appreciate nature.** Stop and smell the roses. Enjoy a sunset.

**24 Pray, meditate or visualize.** Spend time in quiet contemplation or buy/borrow a meditation tape. Fill your mind with healing images and messages.

**25 Enjoy the company of a pet.** Pets are great companions and, except for parrots, they don't talk back. To change kitty litter, you may want to wear a mask and gloves, or ask for help.

**26 Massage, accupressure.** Non-sexual touch can help you get more comfortable with your body. Trade massages with a friend. Some organizations offer free massage.

**27 Check out an AIDS organization.** Ask for what you need. Find out what they offer... a retreat, education, childcare, benefits counselling, or an art class.

**28 Take life one day at a time.** Break big tasks into smaller, manageable ones. If necessary, take life one hour at a time. Tell yourself, "I don't have to know how I'll make it through the week. I just need to gather the strength to make my first appointment with the doctor."

**29 Get involved.** Join a speakers bureau to educate kids about AIDS. Volunteer at an AIDS organization. Become an activist. Call your legislator. Stuff envelopes. Make phone calls. Don't worry that you don't know the lingo or that you're new. Everyone has something to contribute to the fight against AIDS.

**30 Remember that ...** you are not alone!! 

Rebecca Denison is the founder of *WORLD* (Women Organized to Respond to Life-threatening Disease, [www.womenhiv.org](http://www.womenhiv.org)) and the editor of the *WORLD* newsletter. She's been living with HIV for 20 years and is the proud mom of 7-year-old twin girls.

From *WORLD*, June 2000. Reprinted with permission.

# The Goddess Is Flesh Club

## HOW HIV IMPROVED MY SEX LIFE AND GAVE ME GODDESS STATUS

*by River Huston*

**You may have read the title of this article and thought, “This girl must be deranged!”**

But before you have me committed, please read on.

When I found out I had HIV, I thought my sex life was over. I'd never kiss again, let alone have sex. There would be no dating, no relationships, no children. I'd die alone in the hospital, untouchable, unlovable.

Actually, my issues around my sexuality began long before I was diagnosed with HIV.

At the age of 14, I was sexually wounded. This affected me in so many ways, especially when it came to trusting people. However, I believe that the most damage I suffered stemmed from my family and the media. Like most women, I grew up in a world that advised me that my looks and body were my most important assets.

Unfortunately, I didn't get off to a good start. I was a chubby little tyke who no one cooed over. Usually the response to stumbling across me was: “Will she lose all that hair?” I never felt especially cute, and growing up with a mother who was obsessed with looks didn't help. I remember at age 6 asking my mother, “Am I pretty?” Her delayed reply was, “Not really, but at least you won't have to watch your looks fade.”

As a teenager, my self-esteem was below sea level. Yearning for love and affection, I went on a journey, searching for approval, which took me to places I don't recommend — the world of drugs, anorexia and eventually prostitution. I saved and polished every hurt that curled out of the mouths of such wise sages as some John who told me, as I straddled him, that I was quite attractive in the dark. I had a little affirmation that I said to myself in those days: “You're 25 years old, you're a piece of shit and you deserve to die.”

It was a man with a few kind words and information about 12 steps who steered me in another direction. When I got sober, I embarked on a spiritual journey, went to therapy, found a higher power and started to change my life. My self-respect sprouted when I returned to school to get a health degree. I supported myself as an aerobics instructor and fitness trainer, which fit in perfectly with my ever-present eating disorder.

In my last year of college, that all changed.

### *Burger queen*

I'd met the man I thought was The One — and he felt the same way about me! I had finally reached a point in my life when I didn't feel I had to sleep with someone just because they smiled at me, so we'd been making out a lot but we hadn't had sex yet. He suggested we get tested for HIV. Without thinking about how that could potentially completely change my life, I walked into the health department and had my blood drawn.

Two weeks later, I was told I had HIV. My boyfriend followed me as I ran from the office. He tried to comfort me, but as we got off the train and went our separate ways, I knew the relationship was over. I headed straight to the diner. I walked through the door, sat down in a booth and ordered French toast, syrup and butter. It was so good I ordered another. HIV...who cares?!

For the next year I explored the mirror image of starving/bingeing. I ate everything, as much as I wanted. Sometimes I stuffed myself until I was ill, and other times I gleefully ordered a burger, fries and chocolate shake and

felt satisfied. Up until that point, I'd spent my whole life monitoring what went in my mouth. I'd starved, vomited and compulsively exercised to maintain a certain weight. Some people are afraid of spiders or the dark; I was afraid of Hellmann's.

But, suddenly, with HIV, all bets were off and I could have anything I wanted. I was going to die soon, so what did it matter? Besides, food is a perfect anesthetic and I wasn't feeling a thing — including all the initial terrors about being HIV+. Not feeling desirable? A glazed donut or six can fix that. Waking up in the middle of the night afraid I'm going to die alone? Don't worry, have some buttered noodles.

I didn't even realize I was putting on the pounds at rapid speed. Needless to say, my aerobics classes thinned out as I got thicker, and eventually I could care less if you had six-pack abs or the perfect butt because all I wanted to do was hibernate. I moved back to the small town where I was born and that's where I discovered I was a sex goddess.

## *Fat is phat!*

In those days, I didn't look too closely in the mirror. I wore a new size, called One Size, and favoured flowing, floral prints. One day a friend came by to show me some photos she'd taken at a party. I pointed to a rather large woman with a double chin and asked who she was. My friend said, "That's you!" That's when I realized how big I had gotten. I'd gained about 80 pounds and had been doing a good job of ignoring it, but now there was nowhere to hide. I thought, I'll go on a diet, but did I want my last meal on earth to be a Slimfast shake? No!

Instead I started the Goddess Flesh Club. The only requirement was to celebrate cellulite. I couldn't get anyone to join, so I set out solo to love my fleshy self.

My first step in loving myself was to love others. I needed to change my perception of what was beautiful, so I designated all women in the universe as goddesses and went on a sightseeing adventure. No matter what shape, age, size, race or style, I could find something spectacular about any woman I encountered. As my perception of others shifted, it slowly started to shift for myself, though admittedly this was a lot harder.

I'd been picking myself apart for so long that the litany of flaws I possessed seemed endless, so I had to move slowly. One thing I did was ask myself a simple question: *What did you do to be so awful?* I had no valid answer to that question. I rummaged through all the hurts I'd collected in my lifetime — from the playground taunts of Sweaty Betty and Wilma the Whale to the hurtful brother who told me I was a fat, ugly pig throughout my entire adolescence.

I needed new input. I gave myself one hour each day when I didn't criticize myself. If my inner loudspeaker called me a fat, ugly pig, I gently told myself that's not true. Hours led to a day and days led to a lifetime, which brings me to today, when it's become rare for me to call myself anything but lovely. But I am getting ahead of myself.

I had to accept my fat but I wasn't ready to look at it. So I'd light candles, play music and touch the parts of myself I abhorred — my thighs, lower belly, ass. I'd talk to my body and tell it how soft it felt, and eventually I was able to face the mirror and remember to admire, not analyze. It also helped to turn off the TV and stay away from those horrid women's magazines that proclaim all my imperfections every month. The funny thing was, when I began to feel better about my body I didn't need to stuff my face anymore. I just ate when I was hungry, and some weight came off, but that wasn't the point. When I finally came to from my food-induced oblivion, I had to start dealing with having HIV...which included dealing with my sexuality.

## *Sexual revolution*

When you reach a certain weight in this culture, you disappear. My weight gain was a way to pad myself from sexual attention. I used to think it was safer to be fat than to meet some nice guy and eventually have to tell him I have HIV and watch as he goes through the gamut of disbelief, disgust and eventually the need to depart. Some guys have stayed; granted, they wouldn't be men I'd choose to be with if I was HIV negative, but, feeling like damaged goods, I thought it was all I deserved.

## *How to Find your Inner Goddess*

- **When looking in the mirror, admire don't analyze!**
- **Start a love affair with yourself** that includes gifts, kindness, encouragement, and a vibrator.
- **Find a part of your body that you love.** (For me, it was my hands and my feet.) Focus on that body part until your admiration spreads to the parts you loathe.
- **Write a letter to whatever part of your body (hump, belly, legs) is upsetting you** Have that part of your body write a letter back.
- **Treat yourself like your best friend.** Your best friend would never comment on the size of your stomach.
- **Encourage other people's goddesses to come out.**
- **Shift your perception and find something beautiful in each person you encounter.**
- **Be kind and gentle in uncovering your beauty.**

## Laurette Levy, 46

*Diagnosed with HIV: 1991 (infected since 1985); CD4 count: 600; Viral load: undetectable. Writer. Volunteer at Voices of Positive Women. Toronto, Ontario*

When I was diagnosed, I'd been living with my partner and his son for three years. We were planning to buy a house and the future looked rosy. Six months after my big news and his seronegative status, my partner left after having broken up with me via telephone. Very courageous indeed! After that, I stayed alone for two years. Then I met a wonderful man who, when I finally told him about my status, took me in his arms saying, "It's OK, I love you anyhow." A few years later we were happily married...or so I thought.



Although we were very aware of the risks and always practiced safe sex, my husband got more and more afraid of being infected. So I became less and less proactive sexually and we ended up sleeping in separate rooms. For the first time, I started to feel ashamed of having HIV – me, who has always defended the rights of HIV+ women! That was unbearable. The failure of our marriage wasn't totally linked to HIV, but it had a lot to do with it.

HIV has changed my relationship with my body. At first, I didn't see my body differently because I was healthy. There was no visible sign of the disease. But when I started to get

sick and take drugs, my body changed. It's difficult to deal with, especially for a woman, because the image of the female body is so strong in our society; you have to be thin, young and beautiful. When you hit your 40s, your body changes, and mine changed in a strange way. My arms and legs got skinnier and my breasts got bigger.

In my mind, I'm still desirable. It's always pleasant to feel that a man is looking at you. But my body isn't desirable anymore because it's become a danger. In the last few years, I've avoided meeting partners because I don't want to explain my situation. I'm still very afraid of being rejected, so I protect myself by not meeting anyone.

There are a lot more HIV+ people out in the gay community than in the heterosexual community. Gay people know what HIV is. They have sex. It's quite different for a woman. Many HIV+ women don't even have sex with their partner. True, there are other things, like tenderness and massage, but it wasn't the case for me. The HIV+ women I know who do have sex lives are younger. So, with me, there may also be an age problem.

Personally, I've given up on sex. I find that HIV negative heterosexual men are not willing to have a relationship. I hope it's not the same for every woman. When your partner is HIV negative, it's important to discuss the issue. You can have a different sex life that's more geared toward tenderness and massages, touching the other person's body. You have to keep an open mind, be willing to explore new things, not always penetration or things you used to do when you weren't HIV+.

Don't be afraid to talk about it. Don't be ashamed to be HIV+. Don't feel plague-stricken and don't let anyone make you feel this way. We can't let that happen because it's extremely unfair and painful. We cannot accept that. ❌

## Brigitte Charbonneau, 56

*Diagnosed with HIV: 1994; CD4 count: 775; Viral load: undetectable. Vice-chair of Bruce House. Ottawa, Ontario*

The meds and my HIV status affect my sex drive. Sex drive? What does that look like? What does it feel like?

I had to resort to testosterone shots once a month. This month I had my fourth shot, and my sex drive is slowly coming back. I know it'll never be what it was before I was diagnosed, but if I didn't take the shot, my partner would have to wait for sometimes even three months. We've been together six years and I've never heard a complaint from him. Intercourse isn't one of the things I'm into, because I'm terrified, even if my partner wears a condom. But we do have it sometimes. I try to protect him from getting infected. I wouldn't let anyone get infected like I was. I live with HIV and I know what it's like. So we improvise a lot. We're into sex toys, movies, the Internet. I call this a healthy sexual relationship.

I don't know what I'd do if my partner and I split up. I feel totally blessed. He's the first man who's accepted me for who I am. He also loves my grandchildren as his own. When we met, I didn't tell him about my status for the first six months. When I finally did, the only thing he asked me was: "Do I have to worry about anything?" I said "never," and it was never brought up again.

This relationship is a safe haven for me. My second husband infected me with HIV. I lived away from home for a long time, but I kept going back to him because I thought he was the only man I could have sex with. I went back not because of love or respect, but because of sex. Now I know the world can be filled with love and respect. ❌



## Aromatherapy blend

**SENSUAL AROMATHERAPY BLENDS:** In aromatherapy, "scents" refers to essential oils that are used to promote physical, emotional, mental and spiritual well-being. Essential oils, when inhaled, act on the limbic system, the "emotional centre" of the brain, which is also responsible for our sexual behaviour and response. Use the following blends to create a mood for intimacy with a special someone in your life – even if that special someone is you!

**The Sensual Blend:** For massage, mix these essential oils in 25 ml **grapeseed oil** : **mandarin** (5 drops) **sandalwood** (4 drops) **clary sage** (3 drops). Or simply add the oils to your bath.

**The Exotic Lovers' Blend:** For massage, mix these essential oils in 25 ml **grapeseed oil**: **jasmine** (3 drops) **sandalwood** (5 drops) **rose** (4 drops). Or simply add the oils to your bath.

**The Seductive Bath Blend:** Add these essential oils to your bath: **ylang ylang** (2 drops) **patchouli** (2 drops) **orange** (2 drops)

**Caution:** Avoid getting oils in your mouth or eyes. Undiluted essential oils should not be applied to the genitals. Some essential oils should not be used if you are pregnant, have high blood pressure or suffer from epilepsy, so be sure to consult with an aromatherapist.

Provided by Hazra, certified aromatherapist

With the celebration of my juicy, ripe curves came a confidence about myself regardless of my diagnosis. After my goddess transformation, I felt I could disclose and hold my head up. I learned to feel people out first before breaking the news. For instance, when a guy asked what I do, I'd say I work with HIV+ women. If he seemed OK with that, I'd take it a step further and talk about a friend who's positive. If he reacted negatively at all I wouldn't give up, but I'd give myself some warning that this might be a little difficult and perhaps hurtful, and I'd evaluate whether I wanted to go further. (Should I get to know him a little, educate him before I disclose or just walk away because he's not worth it?) I now know that I'm a fabulous, sexy woman and only a fabulous, sexy man will do. (Sometimes they're hiding under an ignorant shell but it's essential that none of us settle.)

I've had long-term relationships and one-night stands with HIV negative men. And I always disclosed no matter what because I just can't relax and have a good time unless I'm up-front about my diagnosis. I tell men that they're safer with me because they know for sure and won't put themselves at risk. Just explaining "safe" can be erotic; it goes beyond a condom. In some way, I look at the AIDS epidemic as a sexual revolution because now, in order to be safe, we have to talk about sex and get specific. And if I'm going to all the trouble of disclosing, taking off my clothes and bringing out the equipment (condoms, dildos, vibrators, food items, outfits, etc.), then I'm going to risk saying exactly what I want and how I want it.

I'd been a receptacle my whole life, focusing on the pleasure of my partners. But as an HIV-enhanced sex goddess, my sexual experience now begins with communication and leads into experimentation, which turns out to be exciting for my partners as well as myself. This goes far beyond barrier sex (condoms, dental dams and gloves); it delves into role-playing, fantasy and making sex an event, not just a roll around the bed that ends in orgasm (and usually not mine).

Sexual adventure can also be solo. I certainly didn't feel like I was settling when a few years ago I decided to forego relationships for a while and focus on *moi*. For my sexual pleasure, I engaged in masturbation. Masturbation is definitely *not* settling; I know exactly what feels good for me, I can make it last as long as I want, and I can do it with whoever I want because the biggest sex organ we have is our minds.



River Huston, 42, is an award-winning poet, author and journalist who is currently performing her one-woman show, *Sex, Cellulite and Shopping: One Girl's Guide to Living and Dying*, across North America. Snippets from her book, *A Positive Life: Portraits of Women Living with HIV*, can be glimpsed on her website, along with photos of her dog, Buddy, at [www.riverhuston.com](http://www.riverhuston.com).

## Finding Mr. Right

A couple of years ago, an amazing man came into my life. He didn't fit the profile of what I thought my mate would be, but he's an incredible partner. I never had to formally disclose to him because in my small town I'm the local loudmouthed activist. In our serodiscordant relationship, HIV is rarely an issue (his refusal to be intimidated by HIV between the sheets is one of the reasons I've become so attached to him). We have other concerns — he's 14 years younger than me and sometimes I have to really work on my body image again because he looks like he walked out of a Calvin Klein ad. But I'm his goddess and he reminds me at every turn. It's been a blessing I never thought possible. In all my past relationships, even when I'd stopped settling, I always felt a nagging dissatisfaction that they were not The One. That doubt has now melted away like buttah on a griddle.

Our lovemaking has ranged from amazing to stalled in its tracks; sometimes it's erotic and sometimes it's more loving and comforting. There are times when I don't feel like having sex. Maybe it's because I'm having side effects from treatments or an infection or I just don't have the energy or desire, but I've learned in this relationship that we have to be honest, open and willing. I also need to recognize the reason behind my sex drive or lack of. Sex isn't everything, but it is important. Besides being fun, pleasurable and even spiritual, it's a way to stay connected.

So, after we spent six months renovating our house and stopped having sex out of sheer exhaustion, we needed to talk about making time and finding ways to stay sexually connected. There have been times we've played out a fantasy that he's still into and I've become bored with, so I've had to find ways to introduce things into fantasy that excite me again. When I'm having an ugly attack, which usually indicates to me that I'm having some other insecurity, I can talk to him about it and he can talk me down. I don't have to ask, "Honey, am I disgusting?" Instead I ask him to tell me what he likes about my body, and for him the list is endless...so endless that he recently got down on his knees and asked me to be his blushing bride!

I know I've found someone extraordinary. But I also know if I hadn't found him, I'd already found myself...someone equally as magnificent. And after 12 years of healing, I always know the right things to do and say to remember that I am a goddess. ♀

### RIVER'S TOP 5 GODDESSES

- | My grandmother May
- | Madonna
- | Rita Mae Brown
- | Lucille Clifton (the greatest poet who ever walked the planet)
- | Eleanor Roosevelt

## Janet Connors, 47

*Diagnosed with HIV: 1989; CD4 count: over 600; Viral load: undetectable. Wannabe retired AIDS activist. Hatchet Lake, Nova Scotia*

**F**rom the moment we're diagnosed, we begin a struggle to remain a whole woman. First and foremost, what we tend to become is a walking, talking virus. You become defined by your virus: You're an HIV+ woman. You're not young, old, a mother, a woman of colour, a schoolteacher...I don't think that happens with men.

Still to a large degree, there's a pretty dehumanizing element within the medical community.

In some of my earlier experiences, somehow there was the assumption that I have the virus and therefore I'm not sexual anymore, I don't really have the right to be sexual anymore. And, if I'm going to be, the onus for prevention of pregnancy and infection falls on me.

I cannot tell you how many times people (both within and outside of the AIDS community) said to me after my husband died: "Surely you can find a nice straight HIV+ guy out there." As if the only person I could ever date again has to be HIV+. To me, that puts us into some kind of second-class place. So, it's not bad enough how dirty or infected you feel once you're diagnosed, but now you're second class and you can only date an HIV+ man. I think it also speaks volumes about the perception of HIV+ men.

My husband, Randy, has been dead for nine years and I've been with my partner for three years. For six years I didn't date. I completely withdrew. I was in mourning for Randy, and because his experience showed me what I could expect, I was also mourning the loss of my own future. I threw myself into work. And I surrounded myself within the gay community. It was kind of like being at a smorgasbord with your mouth wired shut, surrounded by beautiful, intelligent, attractive, interesting men that I could never have.

My partner Terry and I met at a single's dance for "older" people. It had nothing to do with HIV. My best friend convinced me to go to these dances. It was my first big leap back into the straight social world. I met him at the third dance I went to. His response when we talked about my HIV status was: "Well, quite frankly, I probably feel safer with you than I would with any other woman. Firstly, you know you have HIV, and secondly, you probably know more about HIV prevention than any other woman in this province."

This past December, Terry gathered our combined family and literally got down on bent knee and proposed to me.

There are so many people working against us continuing to be a complete or total woman, and it's a battle, but we can do it. 

Photo of Janet: Michelle Valberg



## Sally Richard, 54

*Diagnosed with HIV: 1993; CD4 count: 525; Viral load: 86,700. Riverview, New Brunswick*

**I** got HIV in 1982 when I had a blood transfusion, but I wasn't diagnosed until 1993. I didn't cry when I found out. I went outside, got into my car, lit a cigarette, got a pop somewhere and got lost for a while. When I got home, I told my husband and said he'd have to wear condoms from now on. He refused and turned on me. I left him after my diagnosis because he was an alcoholic and you can only take so much. When I told him I had HIV, he got worse. So I left.



When I was diagnosed, my parents and five siblings turned their cheeks the other way. I needed their help badly. I was living on \$450 a month. I didn't care if I lived or died...until Jack, my spouse, came along. If it hadn't been for him, I'd be six feet under. I feel hurt by my family because they avoid me. My brother Michael is the only one I see; he comes to play bingo with me.

My mother told me, "Don't go around telling people." But I don't want to keep it a secret. I've got nothing to hide or be ashamed about. People have put me down: "Sally Richard, she's a whore." I've had someone throw a hot cup of tea at me. I've been barred from a couple of bingos.

When I go to bingo, my mind is clear. I listen to the numbers called out and I concentrate on that. A couple months in a row, I won \$500! I'm not tightfisted. I've got a heart. But in some ways, I've got a heart of stone because people have hurt me. I've been broken-hearted too many times, so I've become tough. I've been hurt from a child up. You can only take so much in your life. It's important to stay away from people who upset you because it can lower your T-cell count.

I've never come across a woman in my category who got HIV from tainted blood. I wish I could sit down and talk with someone like me about how she feels, what she's gone through and how long it took for her to accept it. What troubles did she go through? Did she have family to help her? At times, I wonder about all this. 

# In • te • grate

**TO MAKE WHOLE OR COMPLETE BY ADDING OR BRINGING TOGETHER PARTS. TO UNIFY.**

*by Barb Findlay*

**HAVE YOU EVER USED ACUPUNCTURE TO LESSEN YOUR PAIN OR FATIGUE?** Taken echinacea, zinc and marshmallow root for a sore throat? Practiced guided imagery or breath work to help you settle to sleep at night? If so, you're not alone!

Nearly half of all Canadians are taking a more individualized approach to their health care these days — choosing to combine safe therapies, products and practices from across health belief systems in a way that works for them. Most often, it's people living with chronic illness who seek complementary ways to manage their symptoms and improve their quality of life. Those living with HIV/AIDS are perhaps the strongest advocates for this type of health care, as many who were diagnosed before Western pharmaceutical treatment was available relied on things like nutrition therapy, mind-body awareness and traditional medicines to keep them well. And women more often than men are drawn toward this holistic way of understanding and managing their often-complex health concerns.

I often wonder about the relationship between women and integrative health care. Has it evolved as a result of women's historic "health-tending" role in our families and communities, and the natural opportunity for exploration that this role provides? Does it have anything to do with the verbal sharing of health stories, experiences and outcomes that women are so comfortable with? Does it sadly reflect firsthand knowledge of the relationship between emotional dis-ease and the onset of chronic illness in women? Is it supported by a gender preference for "process" over "solution"? If so, how does this translate into health-seeking behavior and choices?

The Tzu Chi Institute in Vancouver, British Columbia, has a vested interest in answering some of these questions. As Canada's leading advocate for integrative health care, the nonprofit institute is committed to expanding the possibilities for wellness and quality of life in our society.

Our work is carried out through clinical research and information/education initiatives and partnerships. Women comprise 70% of our clients, the majority of them reporting three or more health concerns — most related directly to a chronic illness. We are deeply interested in the reasons people are attracted to integrative health care. A main focus of our research is to explore the decision-making process people engage in around "integration," their eventual choices and, of course, the related health outcomes.

Evaluating the effectiveness of an integrative approach is a critical next step for organizations like ours. Funders of health care, such as the provincial ministries of health, want to know if there is a cost-benefit to the health care system when people engage in integrative health practices. Do they have fewer emergency room visits? Do they use fewer pharmaceuticals to manage symptoms? Do they visit their family doctors as often? How much are they spending outside of the publicly funded system?

For this type of research to be sound, integrative health care must be defined clearly enough to measure results within a consistent framework. While there's no widely accepted definition in this emerging field, there is growing agreement among patients, health care providers and researchers that it embraces many of the following principles:

- It's based on an equal partnership between patient and practitioner and honours the patient as the expert of his or her own health.
- It involves care and treatment of the whole person — mind, body, spirit.
- It enhances a person's built-in healing abilities.
- It favours "working with people" over "doing to people."
- It values quality of life and wellness outcomes as highly as it does a cure.
- It acknowledges synergy as a healing principle: The whole is greater than the sum of its parts.

- It employs an interdisciplinary, collaborative approach to care and decision-making.
- It respects diversity.

Over the past decade, the emergence of integrative health care has begun to push at the edges of our publicly funded health care system — nudging it toward a more respectful, collaborative way of being. As witness to this evolution, I am humbled by the thought that this movement was initially driven by a handful of courageous individuals determined to take an integrative approach to their own healing without the benefit of scientific evidence or the increased professional awareness that exists today. I have no doubt that many of them have been women living with HIV/AIDS. ✂

Barb Findlay is the executive director of the Tzu Chi Institute ([www.tzu-chi.bc.ca](http://www.tzu-chi.bc.ca)). She is also a CATIE Board member. At press time, the Institute regretted to announce that it was closing as a result of government funding cuts.

### Penny Bradford, 50

*Diagnosed with HIV: 1992; CD4 count: 390; Viral load: undetectable. Chair of the Victoria Persons With AIDS Society. Victoria, BC.*

I'd like to share some words of hope with other women. When I was diagnosed, at 40, I didn't think I'd ever get to see any of my grandchildren. I thought I was quite a long way from being a grandmother, and this really made me sad. In 1996, though I was very reluctant to believe in them, I started on the new medications. After being on and off them for the past six years, I now feel very hopeful. I'm expecting my second grandchild! It's such a joy in my life! I'm so glad I didn't miss it. Thanks to the meds and complementary therapy, I feel much better than I used to.

I'm very open-minded. I take **vitamins** and **supplements**. I do **yoga**. Through yoga I'm learning the art of being kind to myself and listening to my body. I have **acupuncture** and **chiropractic treatments** regularly and have just recently started **Ayurvedic** and **homeopathy** treatments as well. I'm trying to be more nutrition-minded. Regular walks are next on my agenda.

I've been meaning for a long time to get into **meditation**; one of these days I'll make it. I'm trying to have quiet evenings at home, when I don't turn anything on: no TV, music, nothing — just silence. I believe in mind, body and spirit — they all go together. I find **prayers** helpful. And I'm really learning a lot about my boundaries. Don't give more than you've got. Know where your line is. I'm getting to know where my line is more and more each day. I try to be whole and happy, try to strive toward balance in my life: so much time for volunteering, so much time for myself and my grandchildren. I haven't achieved this balance yet — and I don't know if I ever will — but it's an ongoing process. ✂



### Hazra, 46

*Diagnosed with HIV: 1994; CD4 count: 1,100; Viral load: undetectable. Aromatherapist. Reflexologist. Reiki practitioner. Student. York Region, Ontario*

After my diagnosis, I started seeing a **naturopath**, who works together with my doctor. I take **homeopathic remedies, supplements** and **herbs**. My naturopath designed a special program for me that includes vitamins C and B and N-acetyl-cysteine (NAC). Depending on what's going on in my body, I add other things. For example, I take folic acid because at some point I started having abnormal cells in my cervix. Calcium and magnesium help me deal with cramps. I also take evening primrose oil. Recently I added alpha-lipoic acid because, due to the medication, my triglyceride and cholesterol levels were going up. This supplement will bring them down and help normalize my metabolism.

**Homeopathy** takes into account not only the physical but also the spiritual and mental aspects of one's well-being. When I started it, there were a lot of emotional issues coming up for me. I started seeing a **psychotherapist** and working through those issues, such as the fears inside me that I was holding in. The more I did that, the better I felt. I started to forget that I was HIV+. I'm still in therapy.

A few years ago I debated whether or not to start the meds, as my doctor thought it was a good idea. I had a good talk with my naturopath, weighing the pros and cons, and decided to do so. But meds alone weren't going to be enough for me; I also intended to go on with my supplements. When I started the meds, it seemed that the **nutrients** were replenishing my body and my immune system was getting stronger. My T cells have gone up from 300 to 1,100. My health has improved tremendously.

I've gradually learned the importance of listening to my body. I used to keep getting candidiasis, so I took all the sugar and yeast out of my diet. When I had a fungal infection, changing my diet helped it go away in a few months. Now I sometimes just look at a certain food and if my body screams, telling me not to have it, I listen. When I find that my body is getting tired and says "I can't take anymore," I rest, not necessarily sleep, but read a book or **meditate**. Even **prayers** help, and it doesn't necessarily mean that one has to belong to a certain religion. ✂

### Robyn, 33

*Diagnosed with HIV: 1993; CD4 count: 680; Viral load: undetectable. Homemaker. St. John's, Newfoundland*

I like to **eat well**. I'd like to eat better, but unfortunately the cost of "better" is much more expensive. I try the best I can. I try to get things I can afford: a bit of lettuce, a tomato, broccoli. I take **multivitamins**. That's pretty much it. I get \$187 every two weeks, and I have to feed myself and my two children, and buy clothes and what not! When worse comes to worse, there's always a food bank. You have to do what it takes.

Complementary therapy is expensive, and I need money for transportation. Anything of any cost that makes your life better is a tough choice, as you have to sacrifice something. The AIDS committee here has a PWA fund, and **massage therapy** was one of the things that used to be funded for people who needed it. Now they've cut it, together with some staff, and the funds are dropping every year. Less and less services are available for people like me. ✂

## Sheri Quinn, 36

*Diagnosed with HIV and hepatitis C: 1993; CD4 count: 800; Viral load: 1,500. Community worker at CRISS (Centre de Ressources et d'Interventions en Santé et Sexualité); English editor, de tête et de cœur (CRISS newsletter). Montreal (Quebec)*

I don't take medication because, after nine years, my immune system is still strong. I don't know why the virus doesn't seem to be progressing. I take **vitamins** every day to help keep my immune system balanced. I don't know if this is why I'm still healthy or if it's because of a certain gene I have or something. I take Moducare, plant sterols and sterolins which are known to help maintain CD4 cells. I also take **antioxidants** in the form of whey protein and a multivitamin called Greens Plus. I prefer my **supplements** in powdered form because I feel that my body absorbs them better. (Plus, there's no sales tax in Quebec on vitamins in powdered form.)

Complementary therapy for me is not only vitamins and minerals. I believe in a holistic, healthy lifestyle, which one reaches through meditation, exercise, eating and sleeping properly, keeping stress down, not doing drugs and not drinking too much. I have a drug history, so staying off drugs is important for my health and sanity. I try to make this **integrated lifestyle** the most important part of my life. To relieve my stress, I **meditate, exercise** and talk about what's stressing me out.

HIV and hepatitis C co-infection is an issue we don't talk about enough. There's a lack of information in this area. Hepatitis C treatment has very heavy side effects, is very toxic and doesn't work for everybody. People should be aware that there are **natural alternatives** to detox the liver and lower the enzymes. For example, antioxidants can be helpful. Before I try the treatment – with its level of toxicity and terrible side effects – I will try every single root, herb or plant I can find. ⚡

## Minneh Kamau, 34

*Diagnosed with HIV: 1993; CD4 count: 290; Viral load: undetectable. Volunteer at AIDS Vancouver Island and Victoria People with AIDS Society. Public relations officer at the Cannabis Bias Club. Victoria, BC*

When I wake up in the morning I do **a smudge** – a Native ritual that cleanses me and allows me to meditate about my body and what it is feeling. I learned this from the First Nations people in Canada. All I know about it is that it cleanses energy around the person. You put some sage (not green sage) in a shell, and I have an eagle feather that I use. I set the sage on fire; it bursts into flames and has this very sweet smell. I use the ash to cleanse my face and body. When I do this, I also say: "May my hands do good work, may my brain think good thoughts, may my eyes see you, may my ears hear you, may my mouth speak the truth, may my heart be connected to you. Bless the womb, the fruit of life. May my feet walk the right path." It calms me down, it makes me understand that yesterday is gone and I can start a new day. There is always a beginning and an end to everything, and I never really thought about it before. Before my HIV and coming to Canada, I didn't know this! This **ritual** helps me with my depression and to maintain a positive mood. ⚡



## Andrea Rudd, "over 40"

*Diagnosed with HIV: 1988; CD4 count: 1,317; Viral load: undetectable. Artist. Works at various community-based organizations. Toronto, Ontario*

I found out I was HIV+ because I got very ill, first with shingles and a few months later, pneumonia. So it's kind of amazing what good shape I'm in now. I attribute some of it to my constitution: I have good genes and come from a strong stock! But the other thing is that I've been careful about what I consume and I've been taking supplements for the past 14 years. So, the fact that my blood work is so good and my cholesterol and all my counts are normal (my good cholesterol is high!) is also due to (besides the drugs), I believe, **diet and nutritional supplementation**. I take a lot of supplements – **vitamins, minerals, essential fatty acids**. I generally try to eat more **organic, whole foods** and less refined foods. I don't drink alcohol or smoke or do any other drug. Occasionally I go through periods when I get into chocolate (which I consider to be an essential food) and coffee.

It's very costly to take nutritional supplements all the time, but that's always been a priority for me, so I've found ways around it. I worked at a supplement store part-time, so I got a discount. I'm the founder of the Treatment Fund at Voices of Positive Women, which has been going on for about seven years (it was started with a generous donation from comedian Sandra Shamas). We give out either a good quality nutritional supplement package or we reimburse Voices members throughout Ontario for complementary therapies. I'm proud of this program; it would be good if more organizations would start similar ones. Recognition and support of complementary therapies as treatment for HIV is long overdue. ⚡

## Brigitte Charbonneau, 56

*Diagnosed with HIV: 1994; CD4 count: 775; Viral load: undetectable. Vice-chair of Bruce House. Ottawa, Ontario*

Lack of appetite is a side effect I get. I use **pot** to help me with this. I smoke before breakfast, I get the munchies, raid the fridge and eat anything I can find. But I don't smoke it around my grandchildren, so it's difficult for me to eat when they're around. My meals are half the size of those of my 8-year-old granddaughter.

In the summer, I'm a vegetable and fruit freak, but I can't eat it a lot of it now, it's too rough for my stomach. I have to be very careful with what I eat now, especially if I'm going somewhere where there may be problems with a bathroom, because it just happens. ⚡

## Valerie Ashton, 54

*Diagnosed with HIV: 1999; CD4 count: over 700; Viral load: below 30. Regina, Saskatchewan*

I was diagnosed with HIV after I went into the hospital with pneumonia. When I came home, I had this feeling as if I'd died and come back. I hadn't gone to church in a long time; I stopped after I lost my son in a car accident in 1984. The pain from my loss devoured me and I started partying to get rid of it. When I became HIV+ I wanted to get back into church.

After I was diagnosed, I started seeing people in a different way. I have this yearning in my heart to help others. I want to reach out, to let people know that I know what it's like, I've been there. I find it hard to be my age and living with HIV. If not for my **faith**, I don't think I'd have the strength to be here today. I have nine grandchildren from my two daughters. The Lord has really blessed me! But I don't have any friends who are HIV+ and I'd like to meet more people living with the virus. I have so much to share with them and so much kindness to offer. ⚡



# Transcending BARRIERS

LETTING GO OF THE THINGS  
THAT HOLD US BACK

by Kimberley Johnson

I DROVE TO WORK THIS MORNING THROUGH A POVERTY-STRICKEN NEIGHBOURHOOD with a high volume of criminal activity, crack addiction, prostitution, fighting...the risk of HIV running rampant. For many years I participated in these activities in this very neighbourhood. Back then, I'd pray for the sun to go down; all I could handle was darkness. But I'm no longer blocked from that light. Today the sun was shining and I had a smile stretched from ear to ear. In fact, most days I drive through this neighborhood, gratitude consumes me. I'm 32 years old now with a 3-year-old son, and it's been more than four years since those cold and miserable days. I've transcended the darkness.

**TRANSCENDENCE: "To go beyond the ordinary range of perception."**

Transcendence is the path to living life from a place where anything is possible. It's the concept of letting go of all the things in us that block us from really living, so we can make room for enjoyment and peacefulness within ourselves. It's the lifting of our spirits, the uncovering of our hearts to see the truth in all life has to offer. Living every day with a virus that wants to consume me and end my time here on earth makes transcendence especially important to me.

Transcendence comes at a cost, though. It costs much of what we've become conditioned to. And it costs many of our past ideas about things — such as whom we may blame for our demise, what resentments we may carry about our past, and any low opinions we may have of ourselves. I've worked with many women (including myself) with very low self-esteem. I lived most of my life believing things about myself that caused me to stay stuck

in a place which afforded me very little room to achieve anything. I believed I was ugly, unintelligent, unworthy of being loved. I believed deep down that I was a failure.

These are all lies! I'm none of those things. I had to be willing to let go of these views in order to transcend them...and be free. Many of us want to be freed — from low opinions of ourselves, unhealthy relationships, harsh judgments of others and ourselves, stress, past wrongs (either done to or by us) and, of course, the big one: HIV.

**BARRIER: "A structure built to bar passage"; "a boundary or limit"; "something that separates us and holds us apart."**

Most of us tend to get caught up in the barriers in our lives that are outside of ourselves. I spent a long time feeling bitter about who gave me HIV (barrier) and guilty about whom I may have given it to (barrier). I've spent many hours mulling over resentments about why I got it, why I was addicted to crack, why no one seemed to understand, why all my relationships seemed to fail, why I can't do this and who kept me from doing that (barriers, barriers, barriers...), never really coming up with an answer. The truth is, we may never find out the who, what, where, when or why outside of ourselves. And even if we could accuse someone, what do you suppose they could do about it? No matter who you name as the creator of your despair, there's only one who can transcend it — you! No matter how tragic a situation seems, there is a way to transcend it and make it valuable.

Easier said than done? Try this: Begin by loving yourself. Tell yourself every day how incredibly deserving you are of

a life filled with joy and opportunity. Encourage your children, friends, family, even perfect strangers, to do the same. No matter how corny it sounds, just do it. Do it until you believe it. Do you know how beautiful you are? Tell yourself every day until you believe it. Leave yourself voice messages, write yourself little notes, get a friend to remind you, yell it from a mountaintop. Do it now before you lose the nerve. Do it every day until you know it!

**DESIRE: "To wish or long for; want."**

Desire is the one thing required to begin any form of transcendence from any place. You must be willing to leave behind the barriers that are keeping you stuck in order to move on. This requires only the smallest amount of willingness, which will spring from your desire to be free of something. Then you keep putting one foot in front of the other in the direction of the very thing you seek — a better relationship, peace of mind, a job, improved health...the choice is yours. Though what you let go of may not necessarily go away, transcendence will leave you with the truth about it. My own past lives with me now as a reference, a reminder, something to be grateful for...nothing more, nothing less.

Last fall, I attended the Voices of Positive Women/AIDS Committee of Toronto annual women's retreat. I met women from all over Ontario, some newly diagnosed and some who've been around for years. We ranged in age from early 20s to late 60s. We were a mix of gay, straight and bisexual. We came from various ethnic backgrounds — African, Jamaican, Asian, Canadian, American, Indian — and ate different foods from each other's cultures. We enjoyed each other's company immensely. Besides living with HIV, the common denominator among us was the desire for transcendence. Not a single one of us was without the determination to turn a seemingly tragic situation into a triumph.

My journey with HIV has included addiction, but despair and tragedy can come in any shape or size, some far more subtle yet still equally despairing and difficult to get through.

There is nothing, nothing, nothing, we cannot do. We need only be willing to let go of the past and create the future by being in the moment. *This* moment! And when you give away the inspiration you receive, the world just goes 'round and 'round. ✂



Photo: Jake Peters

Kimberley Johnson is a provincial peer network coordinator at Voices of Positive Women ([www.vopw.org](http://www.vopw.org)). She's also the founder of Lifting Spirits, an organization that offers programs and workshops around making quality life decisions with youth. For more info about Lifting Spirits, call 416.816.0214.

## An exercise in Transcendence

Transcendence means letting go of where you are in order to reach the place you want to be. I've found that identifying my goals is a great way to map out the path that will lead me there. Often, however, setting the goal isn't enough. We must examine the steps to reaching this goal and what is required to get there. For me, the art of writing things down is a ritualistic part of letting them go. So here's something to try. It's an exercise in transcendence, which happens by taking steps toward your desires:

Get a piece of paper and a pen or pencil (not a computer!). Draw two lines down the page creating three separate columns.

**Column 1:** Write down your **ultimate goal**. Don't confuse "ultimate" goal with "step" goals. (For example, my ultimate goal was to be healthy.)

**Column 2:** Write down the **step goals** you need to set in order to reach your ultimate goal. Step goals are the action you take to meet your ultimate goal. (Mine included eating better, quitting smoking and so on.)

**Column 3:** Write down all the **steps** you need to take to reach each step goal. Steps are the action you take to reach your step goals. So, using the same example:

ULTIMATE GOAL	STEP GOAL	STEPS
Better health.	1) eat better	see below
	2) quit smoking	

**STEPS:**

**1) eat better** — find out what foods are good for me, go shopping, ask for support around what I eat from the people I live with

**2) quit smoking** — get the patch or quit cold turkey, join a support group, stay away from smoking areas and/or restaurants (where, of course, I'm ordering healthy food!)

In **Column 3**, each step is where you begin to take action. All too often we burn ourselves out trying to climb the mountain when the first step is right in front of us. If we commit to sticking together through our journeys with HIV, we never, ever have to take that first step alone. For that I continue to be forever grateful. ✂

# Coming to terms

## with HIV

BASIC TIPS ON UNDERSTANDING MEDICAL TERMINOLOGY

by Cathy Elliott Olufs

**Living with HIV is a constant learning process.** Not only are we forced to learn about the disease itself, but in many instances we must learn the medical jargon that's associated with it.

For those of us who lack a formalized medical education, this is often a difficult process. I remember learning early on during childhood that in reference to the human body there were usually at least two, sometimes three, different names for the same part. There was the common term we all learned (head, arm, skin, etc.), and then there was the obscure "medical term." How many of us remember having this one pulled on us in the third grade? "Psst! Hey, your epidermis is showing!" Invariably we glanced down, mortified, toward our genitals, assuming we'd left something unzipped, only to have the other kids laugh and say, "Epidermis means skin!"

For most of us who didn't pursue a medical career, our vocabulary of medical terminology dropped off after high school biology class. I recall during the first few years after my diagnosis striving to learn as much as I could about the disease. I attended countless medical updates and conferences only to come out feeling more confused than when I went in. What in many cases could have been said simply by using good old-fashioned English got twisted around with medical jargon (I guess it's what separates them from us. Talk about a language barrier!).

But, before we criticize the medical profession, we must realize that these powerful and, in many cases, brilliant people to whom we entrust our lives have spent years, and years, and years in school learning this stuff. We can't really expect them to flip back and forth; we need to meet them halfway. It wasn't until I got a grasp on the lingo they were using that I began to understand what they were talking about. In doing so, I began to take charge over my own care.

### The basics

Most medical terminology derives from Latin or Greek. If you didn't take it in school or even if you did, visit the local library and check out a medical dictionary (perhaps your doctor will let you borrow one). *The Physicians Desk Reference* is great to start with. By no means will you become an expert overnight; that takes years. But at least if you can understand some of the words and how they're formed, you'll be well on your way toward making sense of what you read and hear at conferences and updates regarding new medications and research.

First, take a look at the whole word in question. Let's take the word *pancytopenia*. Break it down into the various parts: the prefix, root and suffix. **Pan** is the prefix (meaning *all*). The root is **cyto**, referring to *cell(s)*. And **penia** is the suffix (meaning *a deficiency*). So the definition of *pancytopenia*: *a deficiency of all blood cells*.

Got it? OK. Let's try another. How about *lipodystrophy* (everyone's favourite!). Break it down: **lipo** means *fat*; **trophy** is talking about *growth or development*. And anything with **dys** means *abnormal*. So there you have it. *Lipodystrophy*: *an abnormal development of fat!* Here's an easy one: *carcinogenic*. **Carcin** means *cancer*, **genic** is another way to say *causing*, so "cigarettes are carcinogenic," right? Ta da!

Maybe you're not as enthusiastic about all this as I am. That's OK. I'm sure that as you gradually learn this stuff, eventually you'll come across one of those words that you hear frequently but never really understood, and you'll be able to use this format to figure it out and say, "Ah ha! So *that's* what that is. Cool." ✂

Cathy Elliot Olufs is a treatment advocate at Women Alive, a treatment-focused nonprofit by and for women living with HIV/AIDS ([www.women-alive.org](http://www.women-alive.org)). She's also a member of ATAC, the AIDS Treatment Activists Coalition ([www.atac-usa.org](http://www.atac-usa.org)). She lives in Los Angeles with her husband and has two grown-up stepsons.

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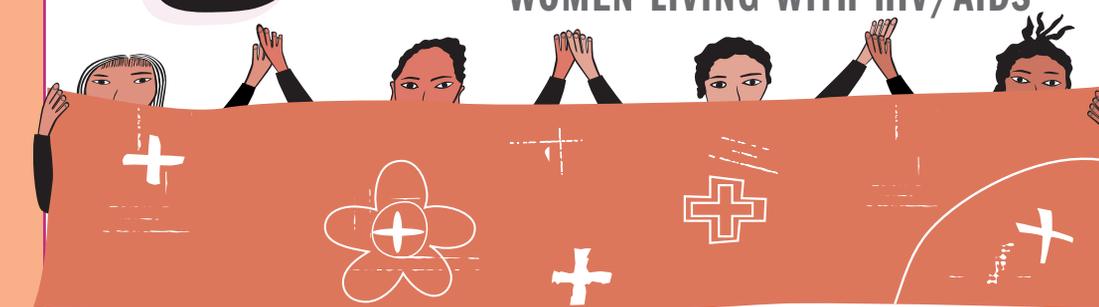
## common terms

The following is a list of commonly used medical terms to start you on your way. Good luck!

- a** = an absence of (for example: *a/vir/emia*)
- aden(o)** = gland (*adeno/pathy*)
- alg** = pain (*neur/alg/ia*)
- anti** = against (*anti/retro/viral*)
- auto** = self (*auto/immune disorder*)
- cerebr(o)** = brain (*cerebro/spinal*)
- contra** = against (*contra/ceptive*)
- cyt(o)** = cell (*macro/cyte*)
- dys** = abnormal (*dys/plasia*)
- emia** = in the blood (*tox/emia*)
- encephal(o)** = brain (*encephal/itis*)
- endo** = inside (*endo/scopy*)
- erythr(o)** = red (*erythro/cyte*)
- gastr(o)** = stomach (*gastr/itis*)
- glyc(o)** = glucose (*sugar*)
- hem(ato)** = blood (*hemato/logy*)
- hepat(o)** = liver (*hepat/itis*)
- hyper** = high (*hyper/lipid/emia*)
- intra** = inside (*intra/muscular*)
- itis** = inflammation (*pancreat/itis*)
- leuk(o)** = white (*leuko/penia*)
- lip(o)** = fat (*lipodystrophy*)
- mal** = bad, abnormal (*mal/nutrition*)
- mening(o)** = membrane (*mening/itis*)
- my(o)** = muscle (*my/algia*)
- myc(o)** = fungus (*myc/osis*)
- opsy** = to view (*bi/opsy*)
- osis** = condition (*fibr/osis*)
- path(o,-y)** = disease (*neuro/pathy*)
- penia** = deficiency (*neutro/penia*)
- oma** = tumor (*lymph/oma*)
- peri** = around (*peri/oral*)
- phleb** = vein (*phleb/o/tomy*)
- plasia** = development (*dys/plasia*)
- rrhe(a)** = flow (*a/meno/rrhea*)
- scopy** = examination (*colpo/scopy*)
- terato** = birth defect (*terato/genic/ity*)
- thromb(o)** = clot (*thromb/osis*)
- tox(i)** = poison (*tox/emia*)
- troph** = development (*a/troph/ic*)

# The Divine Secrets of the Sisterhood

TREATMENT INFORMATION FOR WOMEN LIVING WITH HIV/AIDS



by Lark Lands

Women are different from men. Wow, aren't you glad you decided to read this article? Though this fact may seem obvious, too often in the world of AIDS it's been ignored. Although early concerns that HIV+ women might progress to AIDS more quickly than men have been laid to rest, there are many other ways in which women do, indeed, differ. In order to obtain the best possible treatment for your disease, it is crucially important to be well informed about these issues. Here are a half-dozen things that women wishing to live long and well with HIV should consider.

### 1 LIFE ISSUES

First and absolutely foremost, all the aspects of a woman's life that affect the likelihood that she will be properly cared for must be addressed. Many women living with HIV are caregivers. Some have jobs where they work long hours. Many have lives that are simply overwhelmed by the demands of daily living, to which HIV adds another huge burden. The result may be that taking care of themselves — body, mind and heart — may go by the wayside. And that absolutely must not happen.

Mardge Cohen, MD, the director of Women's HIV Research and the senior physician at Cook County Hospital in Chicago, says, "The biggest issue that women with HIV face is how many issues they face. Managing their medication regimens as well as their jobs and families, worrying about transmission to others, recovering from the difficulties of disclosure, and managing other medical and gynecologic problems are all major issues. For some women, the combination of these medical and psychosocial problems can be quite devastating."

It is estimated that worldwide almost two-thirds of women with HIV/AIDS are caring for at least one child under the age of 16, and for

some this is a task they do alone. In addition, some women are providing care for partners, grandchildren and/or other family members. The emotional focus for many women is caring for their children, a role that may be even more difficult than usual when one or more have HIV. In this setting, many women need to be reminded that if they don't care for themselves, they may not be able to continue caring for others.

It has been found that after HIV diagnosis, women are less likely to use existing HIV care programs, services and therapies initially, and less likely to maintain care down the line. Thus, identifying any barriers to following through on care and addressing practical issues related to obtaining care is very important. Phil Berger, MD, chief of the Department of Family and Community Medicine at St. Michael's Hospital and associate professor at the University of Toronto, says, "Women need to discuss with their doctors and case managers all the possible ways to get the support they need in order to receive good medical care in the most efficient manner." This may include financial and housing assistance, child care and transportation to and from medical facilities. For women dealing with issues such as substance use, domestic violence and homelessness, it may also include seeking support from family members and friends in order to improve their chances for following through with medical appointments and, for those on highly active antiretroviral therapy (HAART), maintaining good adherence to antiretroviral drugs.

Attention must also be paid to problems created by substance abuse and domestic violence. Insufficient treatment for drug problems can create a huge barrier against obtaining proper long-term HIV care. Researchers from the U.S. Women's Interagency HIV Study (WIHS), a cohort that has provided the largest database on women with HIV in the U.S., have found that two-thirds of these women have a history of domestic violence at some point in their lives, and 20% have experienced it recently. Almost one-third have experienced childhood sexual abuse, and these women are more likely to have drug abuse or psychiatric problems. It is very clear that partner violence is a serious problem among HIV+ women. All such issues absolutely must be addressed in order to increase the chances that women will obtain the best possible health care for this disease.

## Second that Emotion

Some women may also need to ask for help getting psychiatric therapy or counseling. At a meeting last year of the Canadian Psychiatric Association, Ken Citron, MD, staff psychiatrist at the Psychiatric Clinic for HIV-Related Concerns at Toronto's Mount Sinai Hospital, noted that people with HIV/AIDS (PHAs) have a higher incidence of mental health problems — including depression and memory or thinking problems related to the disease's effects on the brain — than the general population. He said that treating PHAs requires a certain amount of specialized knowledge about

HIV/AIDS issues, particularly because of the possibility of interactions between antiretrovirals and psychiatric medications. As well, he said, the mental strain of living longer with the disease creates other concerns such as work-related issues. In addition to these problems, women with HIV tend to feel isolated and alone, and may feel ashamed or fearful about revealing their diagnosis to others.

For all these reasons, providing women with emotional support and therapy is very important to increase their ability to manage the disease. In addition to psychotherapy and medications, many women have found help from exercise, mindfulness techniques (such as yoga and meditation), having a pet and HIV support groups. Available in many cities, women's support groups are a great place to exchange information and get the emotional sharing and hugs that too many HIV+ women might otherwise not get. Call your local AIDS service organization to find out if there is a support group for women with HIV near you (and check the resource list on the back page).

## Under One Roof

In order to better provide all of the above, Victoria Cargill, MD, director of Clinical Studies and director of Minority Research at the U.S. National Institutes of Health's Office of AIDS Research, is a strong advocate of "one-stop shopping" care for women: "One-stop shopping means that a woman will be best served if she can get all her treatment needs met in one location. Her medical care and her substance-abuse treatment will be taken care of in the same place. Better still if social services are on site and the place provides child care. Then all of her needs are housed under one roof. It will be so much easier for her to get where she needs to go, and much more likely that she'll be engaged because everything she needs is right there. Not to mention that she won't have to run from one end of town to the other — catching buses, paying car fare and dragging her children around — all at times when she may not even be feeling well."

Having such care centres available to women could greatly increase the chances that women will be able to address all the treatment issues discussed here — and it's sure something that HIV treatment advocates should be campaigning for all over Canada.

Dr. Berger believes that the 410 Sherbourne Health Centre at St. Michael's Hospital in Toronto

comes very close to this model. "At our community-based clinic we provide HIV care, primary care and a methadone clinic," he says. "On staff we have HIV primary care physicians, methadone-prescribing physicians, addiction counselors, and two nurses and a pharmacist who all specialize in HIV. We also have a full-time HIV social worker, along with a half-time HIV dietitian and a half-time occupational therapist."

At the Centre, it isn't necessarily a physician who is the primary contact person. Although all patients see a physician at least six times yearly, each patient chooses whom they'll have primary contact with for day-to-day care issues. For emergencies, there's a 24-hour telephone service for anyone requiring immediate help, and the staff is trained to immediately refer all PHAs to someone knowledgeable about their care. Dr. Berger says, "It's an example of a truly interdisciplinary service where patients have access to all their outpatient needs. We provide a way for women to get all the help they need in one day in one location." For patients who are in extreme financial difficulty, there's even a Patient Comfort Fund, which can provide medications or meet other patient needs on a temporary basis.

## 2 INFECTIONS AND CONDITIONS: DIFFERENCES IN WOMEN

Both HIV itself and the many other infections that may at some point be unwelcome visitors to people living with this disease can have differing characteristics in women and men.

### HIV Itself

HIV+ women tend to have a lower viral load over time when compared to men with similar CD4 cell counts. Researchers have proposed that this should be taken into consideration when doctors are making decisions about starting antiretroviral therapy. Since the current treatment guidelines put more emphasis on CD4 counts (with a general acceptance that therapy should be delayed until CD4 cells drop below 350) rather than viral load, this may be unlikely to change treatment decisions for most women. However, it's always important to watch for new information on such issues and any changes that might be made in future "expert panel" recommendations.

## Opportunistic and Other Infections

Women tend to develop the same types of opportunistic infections (OIs) as men, and in about the same frequencies, but there are several important exceptions. Women have higher rates of esophageal candidiasis (yeast in the throat), bacterial pneumonia and difficult-to-treat (refractory) herpes simplex virus infections. Any new symptoms should always be reported to your doctor so that such infections can be caught early and treated as soon as possible. In addition, although bacterial pneumonia can occur at any CD4 count, chronic yeast problems and refractory herpes problems tend to occur in those with a loss of immune function. Thus, the occurrence of these and certain other infections could be seen as a warning sign that the immune system needs help.

For example, recurrent vaginal yeast infections are far too common and are often the first sign of compromised immune function. Although it's a very effective drug for suppressing these infections, studies show a high incidence of fluconazole (Diflucan) resistance with long-term prophylactic use, so doctors have sought other approaches for controlling the yeasty beasties. McGill University researcher Mona Loutfy, MD, MPH, says, "I'd start with topical treatment for yeast infections. If there is no response, a longer-course treatment of fluconazole often works. However, the best management for recurrent yeast infections is antiretroviral therapy for managing HIV infection and improving the immune system. If this is done, often the problem with recurrent yeast infections goes away." Reducing sugar (yeast's favorite food) in the diet, as well as eating yogurt or taking acidophilus supplements may also help.

## Gynecologic Problems

There are many gynecologic problems that may occur. Sexually transmitted diseases (STDs, like chlamydia, gonorrhea and syphilis) and pelvic inflammatory disease (PID, a serious, potentially life-threatening inflammatory condition in the genital tract, often caused by STDs) are common in PHAs. So, screening for these is a must, both upon diagnosis and any time that symptoms appear that might indicate an infection (pain, cramping, itching, burning, vaginal discharge or odour, painful urination, fever). PID is more likely to lead to complications in HIV+ women than in their negative sisters. It can cause abdominal pain (sometimes severe), fever, discharge, painful urination, cramping and nausea, and must be treated very quickly with appropriate antibiotics.

Human papilloma virus (HPV, the virus that causes cervical and anal cancer) infection and cervical or anal dysplasia (the early changes in cells that may lead to cancer) are common in PHAs. Dr. Loutfy recommends doing cervical Pap smears every six months to screen for changes. She points out that recent

## Tracey Conway, 35

*Diagnosed with HIV: 1998; CD4 count: 620; Viral load: undetectable. Volunteer at Voices of Positive Women, Canadian HIV Trials Network, Canadian AIDS Society, Ontario AIDS Network. Recipient of the Golden Jubilee Medal of Queen Elizabeth II. Sault Ste. Marie, Ontario*

Not only in HIV but in all health-related issues, women seem to come last. The health care system often doesn't realize that women are caregivers and don't have time for themselves. Women need support. Health care professionals have to recognize that gender differences are huge issues. For example, in women, some medications can cause severe life-threatening side effects that don't occur in men. We also need to recognize within the HIV community that women are different from men. We're different in the way we grow up, our societal expectations are different, and we're still generally paid less than men.



The majority of clinical trials are done in men. Whether this is because women can get pregnant or simply because they don't have access — whatever the issues are, they must be addressed. We need accurate information on how the medications work in women. What are the right dosages for women? How do HIV meds affect women in menopause?

One of the many reasons that women aren't participating in clinical trials is because the trials themselves are not made accessible to them. Many women live in poverty and can't afford childcare, and thus cannot dedicate the necessary time to spend at a health care facility that doesn't provide childcare. Covering travel expenses should also be considered as a

way to encourage women's participation. Professionals working in the field should be made aware of these differences. In order to empower women and improve their quality of life, they should know about the choices they have.

Some important questions to ask if and when you decide to participate in a clinical trial:

- How long will it take?
- What types of lab work will be carried out?
- When will the diagnostic testing be done?
- How are they going to monitor the participants?
- When will I receive the results?
- What are the inclusion and exclusion criteria?

You should also know your rights. By participating in a clinical trial or deciding to withdraw from one, your health care will not be compromised.

With more women participating in clinical trials, we'll be able to show any differences in disease progression and care between men and women, improve women's lives, and help women learn how to take control of their health care and make effective and important decisions that are right for them. We'll also have more data about side effects, dosage, viral load and HIV progression that's specific to females. This knowledge will help many women see for themselves the choice of drugs available and the importance of following their drug regimen, without just blindly accepting what their doctor says. We are not men. We are a different and distinct group and we should be heard.

Many clinical trials are not widely advertised, so women don't know about them. It's important to provide more info on clinical trials and their importance, in order to dispel fears about being guinea pigs. Check out the **Canadian HIV Trials Network (CTN)** at [www.hivnet.ubc.ca](http://www.hivnet.ubc.ca) or call toll-free 1.800.661.4664.

Photos: Jake Peters

## Jane Strickland, 40+

*Diagnosed with HIV: August 1990; CD4 count: above 300 Viral load: undetectable. Professional PHA (board member, committee member and advocate at Voices of Positive Women, HIV/AIDS Regional Services, Ontario AIDS Network, Canadian Treatment Action Council). Gananouque, Ontario*

Health is all about positive attitude, not only the meds. Getting myself involved in AIDS advocacy has been a very positive thing for my health. On one hand, it's probably caused me more stress, but it also helps me stay healthy. Because of the networking I do and the information I gather, I can make better choices.



So my advice is: Gather information, become knowledgeable, and know what HIV is, what it does, and what's out there in terms of support. It's important to get connected, build a support network and learn how to speak with your doctor. If you're well informed when you see your doctor, he or she can't just dismiss you. As a former staff member at CATIE, I have a good sense of the pharmaceutical treatments. This knowledge has helped me choose my own treatment. I have a good working relationship with my doctor. The more you know about yourself and the virus, the better you can manage your own health and stand strong and positive...and you don't have to do that alone. The more you know, the more empowered you can become. Support, connection, information and empowerment are all part of being healthy for me.

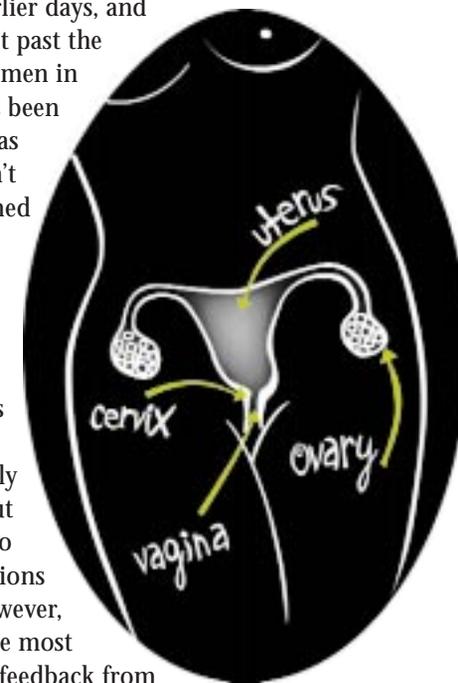
research has shown that, used in conjunction with Pap smears, screening for HPV (with a blood test) is both helpful and cost effective for cervical cancer screening, although it is not the standard of care in Canada. Any abnormalities found with Pap smears would require follow-up testing with colposcopy (microscopic examination) and biopsies (tissue samples), perhaps followed by more frequent Pap smears. Based on the most recent research, experts in the field believe that low-grade cervical squamous intraepithelial lesions (LSIL, early changes in cells) don't warrant treatment because the rate of progression is slow and spontaneous regression (improvement without treatment) often occurs. However, high-grade lesions (HSIL) should be treated. Treatment is aimed at destroying the abnormal tissue so it doesn't progress to cancer. Possible treatment options include: LEEP (removes abnormal tissue with a wire loop); cone biopsy (removes a cone-shaped piece of tissue from the cervix by surgery or laser; frequently used to treat high-grade dysplasia in HIV+ women); electrocautery (burning); and topical solutions. The use of intravaginal 5-flourouracil is often recommended to reduce recurrence after the initial treatment.

Effective HAART has been shown to slow the growth of cervical lesions and even to result in regression, so this would be another consideration when making decisions about starting antiretrovirals. For some women with low-grade lesions, starting antiretrovirals may be all that's needed. In addition, smoking is strongly tied to an increased risk for cervical cancer. In one study, HPV-infected women who smoked one or more packs of cigarettes a day were four times as likely as nonsmokers to develop precancerous or cancerous changes in the cervix. So, need we say it? Throw away the evil weed. Talk to your doctor about finding ways to help you butt out. Although anal HPV infection and dysplasia are also very common in HIV+ women (and men), there are no standard recommendations for anal Pap smears. However, some experts in this field believe that they, too, should become routine. Last but not least, recent research has shown that immunization using an experimental vaccine against HPV type 16, the most common cause of cervical cancers, prevents both infection with the virus and the cervical changes that could lead to cancer. Although the vaccine is not yet approved, its coming availability may spell the end for cervical cancer worries in those not yet infected with HPV.

## 3. ANTIRETROVIRALS: EFFECTS AND SIDE EFFECTS IN WOMEN

Overall, women respond the same as men do to antiretroviral treatment, getting the same benefits in terms of reduced viral load and increased CD4 cells. However, the same may not be true when it comes to drug side effects. Alas, much of the information we have about side

effects comes from the clinical trials that are carried out during the drug approval process. Unfortunately, very few women were included in these trials in earlier days, and even in the recent past the percentage of women in many studies has been low. The result has been that we don't have clearly defined information on the differences between men and women when it comes to the side effects of many drugs, including not only antiretrovirals but also drugs used to treat other infections or problems. However, based on both the most recent trials and feedback from the community, it appears that women may develop different antiretroviral side effects, or at a higher or lower rate when compared to men. Various studies have shown the following:



- The non-nuke nevirapine (Viramune) and possibly other non-nukes may be more likely to cause a rash in women, and the rash may be more severe than it commonly is in men. Nevirapine may also clear more slowly from women's bodies, potentially increasing the risk of liver toxicity.
- Women may experience more gastrointestinal side effects with protease inhibitors.
- Although the overall incidence is rare, researchers have found that overweight women over 40 years are more likely to develop lactic acidosis, a potentially life-threatening condition which has been linked to toxicity to the mitochondria (the energy factories inside cells) caused by nukes (such as AZT, ddI, d4T, 3TC and abacavir). Preliminary research indicates that there may even be an overall increased risk for lactic acidosis in women, in general. The risk also increases if a woman is pregnant.
- There are differences in the likelihood that women will develop certain lipodystrophy-associated symptoms.
- Overall, there is an increased likelihood that women on HAART will experience more neurologic problems (such as nerve damage).

There may be other differences about which we know little, if anything, because of the lack of research or because the differences are not obvious enough to have reached widespread community awareness.

It is not clear what the cause(s) of these differences are. It's possible that some things are genetically determined, and there is ongoing research to study this. It's possible that women's hormones affect the way that the body handles drugs. Researchers believe that estrogens (sex hormones that women produce) may reduce the breakdown of drugs in the liver. Changes in hormones at different phases of a woman's menstrual cycle may also affect the breakdown of drugs.

This may also be a case where size matters. For example, women's livers are smaller than men's. This may mean that breaking down drugs puts a greater burden on a woman's liver. Because a drug is given with a standard expectation for how long it will take for the liver to break it down, if this process isn't working properly, the result may be that too much drug remains in the bloodstream for too long, which increases the likelihood of drug side effects. In addition, women generally weigh less than men. The result may be that standard drug doses are too high to begin with in many women, another factor that could create a higher likelihood of toxicity. Women also generally have a higher percentage of body fat than men, another factor that may cause differences in how drugs work in their bodies.

For these reasons, there's a movement toward doing therapeutic drug monitoring — measuring the level of a drug in the blood at certain points after the drug is taken in order to see if it's reaching a desirable therapeutic level, or one that is too high (increasing the chance of toxicity) or too low (reducing its effectiveness). The results of this testing could be used to adjust the dosage to one that is high enough to be effective but not so high as to increase the likelihood of toxicity and side effects. Some doctors are beginning to use this drug level testing, but it is not yet widely available in Canada.

None of these differences mean that women should avoid taking HAART. The benefits for women who have reached the point where antiretroviral therapy is needed clearly still outweigh the risks. However, women should always ask for complete information on any possible side effects that could result from any medications being given and immediately report to their doctors any new symptoms that develop, not only in the period immediately after starting or changing a medication but at any point down the line when a new problem occurs. Always let your doctor determine whether this or that symptom might be drug-related and might therefore necessitate a drug switch. It's also very important for women to ask for and receive regular lab tests that could indicate drug toxicity or side effects. Included would be very regular monitoring of liver enzymes, kidney function tests, and the levels of fats (cholesterol and triglycerides) and sugar (glucose) in the blood. It's important to set up appointments for obtaining these tests before drugs are started.

## 4. LIPODYSTROPHY

Symptoms associated with lipodystrophy may develop differently in women than in men. This syndrome can cause a wide variety of body changes, including fat accumulation (in the belly and breasts, behind the neck, and in the form of fatty tumours on the limbs), fat loss (in the arms, legs, face and buttocks), and elevated blood fats and blood sugar. Although any or all of these can occur in both sexes, women appear to be more likely to develop significantly increased breast size and abdominal fat accumulation. The weight gain may be more pronounced in women who were overweight to begin with but can occur even in women who were initially quite thin. Some women develop so much additional belly fat that it's common for them to be mistaken for being pregnant. Just as with women who really are pregnant, they may develop serious back pain from the additional abdominal weight. They may also develop digestive problems because of the excess fat pressing down on their stomachs.

Some women also see their arms, legs and buttocks shrink, while their faces become ever more gaunt. The combination of these body changes can be emotionally devastating. Some women feel that their ability to lead a normal life has been taken away. Many feel that the body changes have become a marker for being HIV+, "outing" them to the world. "Too many of my patients feel that they have become marked women," Dr. Berger says. In addition to all these problems, women may also be more likely than men to develop increased blood glucose, although perhaps less likely to experience elevated blood fats. In the WIHS cohort, preliminary data has shown an increase in cases of diabetes in women of colour who are on HAART.

It's very important to have regularly scheduled blood tests to look for any negative changes. In terms of body changes, standards for regular assessments have not been established, but possible monitoring tools include: self-observation (which has been found to be very accurate overall); photos taken of the body at several different angles (beginning at HIV diagnosis and at regular intervals after that); measurements using calipers to measure skin-fold thickness and tape measures to determine arm, thigh, waist and hip circumference.

Technologically, more sophisticated tests that can show changes in body fat include DEXA scans (a kind of X-ray), cross-sectional CT (computed

tomography) scans (another kind of X-ray), and whole body MRI (magnetic resonance imaging) screening. Because of high cost, MRIs and CT scans are not commonly used. Some doctors do the less expensive DEXA scans before patients begin HAART and at regular intervals afterwards in order to monitor body changes precisely. However, because this involves repeated radiation exposure, it's important to discuss the pros and cons of such testing with your doctor.

Approaches to addressing these symptoms include attempting to counter the cause(s) as well as using therapies aimed at the symptom itself. Because it is thought that fat loss is predominantly tied to the adverse effects that nukes have on the mitochondria (the energy factories in cells), nutrient therapies that help support the mitochondria (B vitamins, antioxidants, coenzyme Q<sub>10</sub> and the amino acid L-carnitine) may help prevent the development of this problem. For those with facial fat loss, there are several injectable substances, such as New-Fill (polylactic acid) or fat (taken from the person's own body), that can help restore a normal facial

appearance. For those with fat accumulation, human growth hormone (Serostim) is often effective. Insulin-sensitizing therapies may not only help reverse blood glucose problems but also may help to lessen or reverse fat accumulation. Surgery can be used to reduce breast size, and liposuction is effective for buffalo humps and lipomas. Exercise can help lower blood fats and improve insulin sensitivity, although its effect on fat accumulation is usually minimal.

Because protease inhibitors appear to be associated with fat accumulation and elevated blood fats, drug switches are sometimes tried for these problems. It appears that substituting a non-nuke or a nuke for a protease inhibitor will help lower blood fats, although the effects so far seen on reducing fat accumulation have not been impressive. Drug therapies, nutrient therapies and dietary changes may also help lower blood fats. (For more info on all of these therapies for lipodystrophy symptoms, see CATIE's *Practical Guide to HIV Drug Side Effects*.)

## 5. BONE PROBLEMS

There is growing concern about the occurrence of bone problems in PHAs. Osteopenia (a reduction in bone mineral density that may lead to osteoporosis), osteoporosis (thinning and weakening of the bones that may cause fractures) and osteonecrosis (death of bone tissue that can cause pain and stiffness and may require hip replacement) are being diagnosed in more and more people. Because bone problems take longer to develop than other symptoms, it's not yet clear whether women develop these problems at rates higher than those seen in men. However, women have a generally higher risk of developing osteoporosis anyway, so there is concern that this may become a significant problem for many women with HIV, especially after menopause. A DEXA scan is used for the diagnosis of osteoporosis. A comprehensive physical exam followed, if appropriate, by an MRI scan of the bone is needed to diagnose osteonecrosis.

Many factors may contribute to the development of bone problems. HIV infection itself leads to suppressed bone growth and increased bone loss, possibly through the production of pro-inflammatory chemicals that are part of the body's immune response to the virus. Natural anti-inflammatories contained in fish oil (2 capsules, three times daily with meals) or flaxseed oil (2 capsules, three times daily with meals) or ginger (2 capsules, three times daily with meals, or ginger tea made from chopped ginger root) or curcumin (500 mg capsule, three to four times daily) may be useful. Suppressing the virus with antiretrovirals appears to help normalize these bone processes, but

in a Catch-22, protease inhibitors have been tied to an increased risk of both osteoporosis and osteonecrosis. For women with already present bone problems, this might be an important consideration in choosing medications.

Lowered levels of hormones, including estrogen, testosterone and DHEA, can also contribute to osteoporosis, making hormone testing and possible replacement therapy very important (*see next page*). Nutrient deficiencies that are common in HIV disease may leave the body with insufficient building blocks for bone. A nutrient-rich diet combined with supplementation with calcium (1,000–1,500 mg), magnesium (500 mg; excess magnesium can cause loose stools so beware), and vitamin D (800 IU daily) may help to counter this. Co-infection with hepatitis B or C greatly increases the risk of osteoporosis, with the likelihood of bone problems becoming ever greater as liver disease advances. This is another factor to consider in making choices about treatment of these infections. Other risk factors include smoking, lack of weight-bearing exercise, overuse of alcohol, thyroid problems, adrenal gland abnormalities, and long-term use of corticosteroid drugs. For those concerned about their bones, it's important to eliminate as many of these as possible. Try to quit smoking, exercise

**NUTRIENT DEFICIENCIES THAT ARE COMMON IN HIV DISEASE MAY LEAVE THE BODY WITH INSUFFICIENT BUILDING BLOCKS FOR BONE.**

## Louise Binder, 53

Diagnosed with HIV: 1994; CD4 count: 770; Viral load: undetectable. Chair of Voices of Positive Women and the Canadian Treatment Advocates Council, co-chair of the Ministerial Council on HIV/AIDS. Recipient of the Golden Jubilee Medal of Queen Elizabeth II. Toronto, Ontario

The most important thing is the concept of getting control of your life and feeling a sense of control. I think that starts with a recognition that we do not control many things that happen to us in our lives. What we always do control is how we decide to respond to those things. The more we recognize that that's where the real control centre is, the healthier we'll be as human beings. That's what life has taught me.

So, with this disease: You have the disease, you don't control that. You have only so many options of how you can deal with the disease. But the control you have is in learning everything you can about the disease and the options available to you to stay healthy. Then you can take control of making the right choices for you.

With that also comes control of sickness, not only of treatment in the allopathic or Western medicine sense, but in the sense that people are treatment, too. People are part of our health system. The people

you keep around you have got to nurture and nourish you and keep you healthy. If we stay in violent or unhealthy relationships, that takes control away and it takes health away.

At times when things feel like they're spiraling out control, I take myself back to remembering the areas where I am exercising control. So, I make sure that I'm taking my meds, doing my exercise and eating and sleeping in a healthy way. The other thing I do is literally push through. A therapist once said to me: "Sometimes you have to fake it until you can really feel it." And that's what I do. I remind myself of the things over which I'm still exercising control, and then I fake feeling good. It sounds strange, but I carry on as if I'm feeling fine, and then it actually becomes the reality. The pretense at the beginning becomes the reality, and I push through and push forward again. I think it's the way to go, it's the only way I know. Otherwise, we're just completely bogged down and we lose our sense of self and our sense of being centered, and that's what we have to keep coming back to. ✂

## Deanna Dugas, 40

Diagnosed with HIV: 1996; CD4 count: 184; Viral load: 24,000. Committee member at AIDS New Brunswick. St. John, New Brunswick

My doctor really wanted me to take the medications, but I didn't want to start until I was really sick. I'm not a pill person. I was worried about taking them because I have a few friends who've gotten sick from side effects. But my CD4 count was getting low, so I agreed to start meds a little while ago. I feel fantastic. I used to sleep a lot because I was always tired, and now with the meds I have more energy, which is great because I really want to try to get back to work. I'm taking a computer course.

I was also worried because I didn't think I'd be able to follow through with the meds and take them at the right times. If you miss taking them too many times, they don't work anymore. But I've been remembering to take them in the morning when I wake up and at night before bed.

My grandchildren and daughter are my inspiration and life. They give me the pleasure of staying on this earth. I believe I stay here to help them. ✂

regularly, avoid over-consumption of alcohol, and treat hormone problems appropriately. Regular weight-bearing exercise (such as walking or weight-training) is particularly important for anyone concerned about bone health. It's the stress of your body weight coming down on your bones when you're exercising that actually stimulates bone growth. So just do it.

There are also possible drug therapies. The use of alendronate (Fosamax) and risedronate (Actonel), two drugs used to treat osteoporosis in post-menopausal women, has not been studied in pre-menopausal women with bone loss, but some health care providers are now prescribing them for HIV+ women who have low bone density. Raloxifene (Evista) is a selective estrogen receptor modulator (SERM) that may help to counter bone loss in women with low estrogen, without the risks of hormone replacement therapy. Remember to always consider drug interactions and side effects before taking any new medication. There are also two alternative therapies that may have benefit. Although not yet studied in PHAs, ipriflavone, a soy-derived bioflavonoid, has been shown in several studies to increase bone density in HIV negative people. Naturopathic doctors have reported good results in relieving bone pain with the use of a Traditional Chinese Medicine product called Marrow Plus, a combination of codonopsis and other herbs that is given in doses of three to four capsules, several times daily. Herbs can also interact with medications, so if you're on HAART, ask your doctor or pharmacist about this. (For more info on countering bone problems, see CATIE's *Practical Guide to HIV Drug Side Effects* and "Good to the Bone," *The Positive Side*, fall/winter 2001.)

## Aromatherapy blend

FOR PMS AND PERIMENOPAUSAL SYMPTOMS:

For massage, mix the following essential oils in 25 ml of **grapeseed oil**:

**lavender** (7 drops) **geranium** (3 drops) **rose** (2 drops)

Lavender is calming, soothing, balancing and relieves anxiety (great for muscle aches and pains). Geranium is a hormone balancer and a good oil for mood swings and depression. Rose is nurturing and uplifting and is also used for strengthening the liver.

Or simply add the essential oils to your bath.

Provided by Hazra, certified aromatherapist

## 6. HORMONES

Research has shown that HIV infection can affect the body's ability to maintain normal levels of hormones — the chemical messengers produced by glands that affect countless aspects of body function. Four of the hormones most commonly affected are: testosterone, DHEA, estrogen and progesterone. These hormones normally stay in balance with each other, and a drop in one can adversely affect the levels of others. Hormonal inadequacy or imbalance can have many negative results, including menstrual problems, moodiness, depression, fatigue, inability to build muscle, wasting, sleep problems, loss of fertility, vaginal changes (often dryness and thinning of the vaginal tissue), loss of bone density (which can lead to osteoporosis) and, last but definitely not least, loss of sex drive and difficulty with achieving orgasm. Far too often, these are ignored or written off as just "living with HIV" when, in fact, they are very important symptoms that should point toward the need for testing hormone levels and doing appropriate replacement therapy where needed.

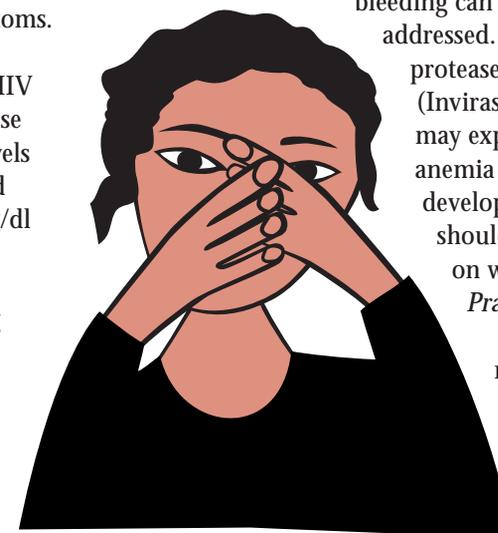
Although testosterone is normally thought of as the male sex hormone, women also need it for proper sexual function and drive, as well as to maintain muscles, weight and energy, and to prevent depression and mood changes. Low testosterone appears to be more common in post-menopausal women, those with low CD4 counts, and those who are experiencing wasting. In addition to the effects of HIV, certain drugs sometimes used in the treatment of HIV-related conditions can also lower testosterone. Included are ganciclovir (Cytovene), megestrol acetate (Megace) and ketoconazole (Nizoral). Although laboratories list a very wide "reference range" for women's testosterone levels, experts say that being on the low end of normal may not be sufficient for eliminating symptoms. According to Jon Kaiser, MD, a California doctor with a large HIV practice who has researched these issues, optimal physiological levels of testosterone in women would be: total testosterone 50–100 ng/dl and free testosterone 1.0 to 2.0 ng/dl. If levels are below this — especially if you're experiencing symptoms like loss of sex drive,

depression and/or loss of muscles or weight or have been diagnosed with bone loss — it would be very important to discuss replacement therapy with your doctor. Many women have found that their sex drive, capacity for orgasm, energy level and overall feeling of mental and physical well-being improve remarkably when their testosterone levels are normalized.

A replacement option for women is the use of testosterone gels or creams which can be prepared by a compounding pharmacist (a pharmacist who mixes up a potion for you with different existing drugs) in the dosage needed to restore optimal levels. Women's individual needs will vary, but most women get good results with a cream that contains 5 mg in 1/4 teaspoon. The 1/4 teaspoon is applied to rotating skin sites (wherever the skin is thin but over a fat-containing part of the body, such as the inner arm, inner thigh or abdomen), twice a day for a total daily dose of 10 mg. Testosterone levels should be re-tested after a month of use to see if the level has been normalized without being raised too much. Overdoing testosterone can cause acne as well as masculinization (facial hair, deepening voice, increased clitoral size) that may not be fully reversible, so follow-up testing is a must.

DHEA is a hormone produced by the adrenal glands that has been found to be low in women at all stages of HIV disease. Maintaining optimal levels can have positive effects on sex drive, energy level, mood, bone health and muscle mass. Experts recommend testing the DHEA-sulfate blood level and, where necessary, doing replacement therapy sufficient to restore an optimal level (in the upper half of the normal range, usually 100–300 micrograms/dl). Depending on the initial blood level, Dr. Kaiser recommends beginning with 10–25 mg of oral DHEA per day and then increasing, if necessary, to reach the optimal level.

The female hormones estrogen and progesterone may also be too low in many women, and the result can be menstrual irregularities, perimenopause (the stage that precedes menopause and may last for many years in some women) or menopause (when the menstrual cycle ceases). One study found that two-thirds of HIV+ women experience irregular periods, skipped periods or vaginal spotting (bleeding between periods), and that the menstrual irregularities appear to be associated with disease progression. Menstrual periods may become irregular and blood flow may be either lighter or heavier than in the past. Heavier bleeding can worsen anemia and so should always be addressed. Studies have shown that women using the protease inhibitors ritonavir (Norvir) or saquinavir (Invirase or Fortovase) or a combination of the two may experience longer periods. (Note that although anemia may only be mild in some women, it can develop into a very serious problem in others and should always be carefully treated. For more info on ways to address this problem, see CATIE's *Practical Guide to HIV Drug Side Effects*.) In many women, symptoms of pre-menstrual syndrome (PMS) can become



more intense, including water retention, abdominal cramps, leg and back pain, swelling and pain in the breasts, irritability, headaches, moodiness, anxiety and depression. Over-the-counter pain medications such as ibuprofen (Advil, Motrin) may help relieve some of these symptoms. Some HIV+ women go into perimenopause or menopause much earlier than is common in their HIV negative sisters. During perimenopause, the menstrual cycle may become shorter or there may be skipped periods or heavier-than-normal bleeding. Some women will develop atrophic vaginitis, a condition in which the vaginal tissue thins due to lack of estrogen and there is irritation and dryness. Other symptoms may include hot flashes, night sweats, insomnia, irritability and lowered sex drive, often occurring even while the woman is still having periods. The same symptoms can occur during menopause, a stage that HIV+ women may reach five to 10 years earlier than is usual. (Menopause normally begins between the ages of 40 and 55. It is a slow and gradual process that occurs over three to five years. Menopause is complete when you haven't menstruated for 12 months in a row.)

Because some of these symptoms can be caused by HIV itself or other serious conditions or infections, it is very important for aggressive diagnosis to be carried out in order to determine all the possible causes. This should include:

- a complete physical
- a pelvic exam
- a Pap smear and/or colposcopy
- screening for infections
- blood count and chemistry and pregnancy test for heterosexually active women
- a review of menstrual history and current medications, along with any history of other drug use
- testing of hormone levels

As a minimum, for proper diagnosis of perimenopause, menopause and hormone imbalances, the following tests should be done: blood levels of FSH, estradiol and testosterone. The tests must be done during the correct days of the menstrual cycle in order to interpret them properly. Day 1 of the menstrual cycle is the very first day you see even a small spot of blood, even if full-blown bleeding doesn't occur for another day or so. The blood for all three tests should be drawn on one of the days from Day 2 to Day 4 of the cycle. An FSH level greater than 35–40 IU for two months indicates menopause. An FSH level of greater than 20 IU for two months indicates perimenopause. An estradiol level that is either too low or too high suggests a hormonal imbalance and may indicate perimenopause.

If tests determine that symptoms are being caused by hormone changes, replacement therapy can be considered.

*Short-term* hormone replacement therapy (HRT) may be recommended for those with disabling menopausal or perimenopausal symptoms, since it will usually relieve those symptoms. However, the most recent research shows that long-term HRT (especially for more than five years) not only does not provide all the benefits it was once thought to (such as protection against cardiovascular disease), it may actually confer serious risks for heart attacks, strokes and cancer. Thus, many experts now lean toward avoiding long-term HRT, if possible. However, all aspects of an individual woman's case must be considered.

For example, it is clear that in HIV negative post-menopausal women, HRT can help prevent osteoporosis. Because there is growing concern about bone loss in HIV disease, in general, and HIV+ women may go through menopause at much earlier than usual ages, the lack of appropriate hormones over a lengthy period of time might ultimately contribute significantly to worsening the osteoporosis problems. In a woman with a family history of osteoporosis or who already has signs of bone loss, this might be of particular concern.

On the other hand, there is a possibility that replacing hormones might increase the risk of breast, uterine or ovarian cancer. Since HIV+ women may already be at increased risk for cancer due to compromised immune function, the possibility that HRT could worsen the risk is a definite concern. In a woman with a family history of breast cancer, this risk would be of even greater concern. There are many other aspects of a woman's health (a history of liver or gall bladder disease, diabetes, uterine fibroids, blood clots, and so on) that must be considered by a doctor before any decision is made about HRT. In the end, all the pros and cons of long-term replacement therapy will have to be very carefully weighed. Because HRT of any kind can interact with certain drugs, this must also be considered before initiating therapy.

After careful diagnosis has eliminated any other possible causes of menstrual irregularities and other symptoms, various approaches to hormone therapy are possible if the benefits are deemed to outweigh the risks. The use of oral contraceptives (birth control pills) may re-establish normal periods in women of childbearing age in whom they have been irregular or missing completely. Using birth control pills can also help solve the problem of abnormally heavy bleeding since they usually promote very

regular, reasonably light menstrual bleeding. This can be very useful for those at risk of anemia.

It's important to remember that many antiretrovirals interact with ethinyl-estradiol, the main ingredient in most birth control pills. With ritonavir (Norvir), lopinavir/ritonavir (Kaletra), nelfinavir (Viracept), nevirapine (Viramune) and, possibly, amprenavir (Agenerase), the Pill may be less effective. With indinavir (Crixivan), atazanavir (Zrivada), efavirenz (Sustiva) and, possibly, delavirdine (Rescriptor), ethinyl-estradiol levels are increased, possibly worsening side effects. Your doctor and/or pharmacist will have to determine if using any of these drugs in combination with birth control pills will require changing the dose of the birth control pills in order to maintain effectiveness or reduce side effects. Another form of contraception may be needed when dosage adjustments are not possible.

For the lower, more physiologically appropriate replacement amounts of hormones normally considered appropriate for perimenopausal or menopausal women, compounding pharmacists can make up hormone-containing creams or gels. For perimenopause, it is common for doctors to prescribe a 10% progesterone cream, 100 mg (1/4 teaspoon) twice daily, applied topically on the chest, abdomen, inner thigh or inner forearm during Days 14 through 28 of the menstrual cycle. For those in menopause, most experts recommend the use of a soybean plant-derived triest (containing three estrogens) cream in a concentration of 2.5 mg/gram. A 1/4 teaspoon of cream is normally rubbed in wherever the skin is thin, twice a day, although the amount can be adjusted based on what's necessary to relieve symptoms. It is thought best to combine this with progesterone, used as discussed above, in order to lessen cancer risk and increase bone growth. For more info on hormone testing and replacement in women, an excellent resource is *Healing HIV: How To Rebuild Your Immune System* by Jon Kaiser, MD, available at [www.jonkaiser.com](http://www.jonkaiser.com).

In addition to HRT, certain dietary changes as well as nutrient supplementation can often greatly reduce or eliminate both menstrual and menopausal symptoms. Vitamin E (1,200–2,000 IU daily) is particularly useful for eliminating hot flashes and sweats, as well as painful or swollen breasts. Magnesium (500 mg daily) can greatly decrease cramping and irritability. Calcium (1,500 mg daily), vitamin B<sub>6</sub> (50 mg, three times daily) and potassium (eat high-potassium fruits like

bananas, melons and oranges, and leafy greens such as spinach) can reduce water retention and moodiness. Gamma-linolenic acid (GLA) found in borage oil or evening primrose oil (480 mg daily) may help with both the emotional and physical symptoms of PMS.

Reducing salt in your diet will also help cut down on PMS-associated water retention and the bloating sensation that many women feel. Cutting back on caffeine can help decrease anxiety and irritability. Because caffeine may exacerbate fibrocystic breast disease (painful lumps) — a condition that may worsen around menstruation — cutting out caffeine-containing coffees, teas, colas and chocolate may be particularly important for women with this problem. Alcohol has been shown to worsen headaches, fatigue and depression in those with PMS, so if it's part of your life, cutting it out during the premenstrual week might be helpful. Massachusetts Institute of Technology (MIT) researchers have found that consuming a combination of carbohydrates that results in an increase in serotonin in the brain can help reduce tension, depression, anger and confusion in PMS'ing women. Any combination of foods that raises the blood level of the amino acid tryptophan will work because it, in turn, stimulates the production of serotonin. Low-fat, high-carbohydrate foods like hot cereal or toast with jam, as well as the protein foods that are high in tryptophan (such as dairy products and turkey) can all work to boost serotonin levels and, thus, your mood.

Exercise may help some women through its ability to raise the feel-good chemicals, called endorphins, in the brain. And, last but not least, energy therapies like acupuncture or Reiki can often very quickly relieve menstrual pain and cramps. Consult a practitioner and you may soon find that very simple techniques can banish menstrual miseries.

## Conclusion

All of this might make managing HIV disease seem overwhelmingly difficult for women, but many do it remarkably well. Dr. Cohen says, "I am always moved by how strong and nurturing the women I care for are, especially considering how many obstacles they've faced and how many they still have to face." By keeping up to date on the latest treatment information, seeking the best available care and support for obtaining it, and remembering that caring for yourself may be the best gift you can give to others who need you, women can greatly increase their chances for continuing to overcome those obstacles and, thus, be able to live both long and well with HIV. 

Lark Lands, a medical journalist and longtime AIDS treatment educator and advocate, was a pioneer in bringing attention to the need for a total integrated approach to HIV disease. The longtime science editor of *POZ* magazine ([www.poz.com](http://www.poz.com)), she is a frequent speaker at AIDS conferences and does her seminar *Living Well...Not Just Longer* throughout North America. For her fact sheets and treatment information summaries, go to [www.larklands.net](http://www.larklands.net).

**CERTAIN DIETARY CHANGES AS WELL AS NUTRIENT SUPPLEMENTATION CAN OFTEN GREATLY REDUCE OR ELIMINATE BOTH MENSTRUAL AND MENOPAUSAL SYMPTOMS.**

# Lady Sings the BLUES

When grief, illness or plain-old hard times turn into a prolonged depression, your health and survival could be at stake. So right when you want to crawl under the covers for good, **IT'S TIME TO ASK FOR HELP – AND GET DIAGNOSED.**

*by David Coop*

**LIFE WITH HIV ISN'T EXACTLY EASY.** It can mean struggling with illness or drug side effects, grieving for friends or family lost to the disease, and facing a future where everything from jobs to relationships is more difficult than it was before you were diagnosed. Any of these experiences is likely to fill you with intense sadness at times — a natural, if painful, part of the coping process. But a recent survey showed that people with HIV and AIDS (PHAs) are particularly vulnerable to sorrow, anxiety or grief turning into a prolonged, paralyzing depression (every day for more than two weeks with no let-up) — a state in which your emotions can begin to damage your health.

The survey of 136 HIV doctors, by the International Association of Physicians in AIDS Care (IAPAC), found that 80% of their patients with HIV suffer from depression or anxiety — more than 10 times higher than common estimates of depression in the population at large. (Other studies have found that women are more likely to experience depression than men, possibly because of the increased stress they often face as caregivers.) And yet, in a related IAPAC survey of 235 PHAs, only 62% reported that their doctors ever asked them about their mental health. This data means two things: One, if you think depression can't happen to you, think again. And two, right when you're feeling the most down, you may have to be the one to reach out for help.

The problem I've found in my years as a psychotherapist is that while physical illness usually prompts people to seek professional help, people often view depression as self-imposed weakness — especially those raised to keep a stiff upper lip. I've often heard patients say, "I just need to snap out of this and think positively" or "I have only myself to blame." Well, it's not so simple.

Real depression is extremely complex. It involves changes in your mood that are so severe and prolonged that you really can't "snap out of it" on your own. In the middle of a depression you can become so preoccupied with your own feelings that you lose the ability to see the world objectively. You can feel completely worthless, hopeless and unable to ask for help. Embarrassment, shame and guilt can often make your low mood sink even lower. You can endlessly replay "old tapes," second-guessing all your past choices — for PHAs, this can mean beating yourself up about the circumstances of your infection or past risk behaviors. Depression is the opposite of seeing the world through rose-coloured glasses; instead, everything looks gray. Even when friends or family are trying to help, their comments may seem critical, painful or frightening. As result, you may pull further into your shell, shutting out the world.

One Canadian psychotherapist (she asked not to be named, to protect the confidentiality of her patients) who's been treating PHAs since 1987 says that depression among women with HIV has its own particular patterns. She sees more "anxious depression" rather than "hopeless depression" in women, who are often overwhelmed trying to cope with their own illness and the illness of a child. This can mean more feelings of anxiety and guilt, often accompanied by eating or sleeping too much. Many women, she says, struggle with "a great deal of enormous sadness over losses and how to cope with

that and get on with life,” while others struggle with the loss of physical attraction stemming from lipodystrophy — the skinny arms and legs, sunken cheeks, and large breasts and belly that can be a side effect of some HIV medications and perhaps even the disease itself. Regardless of gender, many of her patients with HIV struggle with the image that the disease is now supposed to be “chronic and controllable,” but the reality of fatigue, side effects and financial pressures means “you can’t really go back to your former life.” As well, there are stages in living with HIV when the likelihood of depression may be worse, including after initial diagnosis, after developing serious physical illness, or after the death of friends and loved ones.

If any of these stresses push you into a real depression, your health may suffer. You may stop eating and sleeping well or taking your HIV medicines on time or making it to doctors’ appointments — all recipes for a health disaster. At worst, some people experiencing depression take their own lives. So for your own health, and the well-being of the people closest to you, if you suspect you may be on the slippery slope to depression, talk with your doctor. He or she may be able to refer you to a psychotherapist.

## Diagnosis

When you’re in a depression, it can feel inescapable — but in fact there are a variety of ways to treat it. A holistic approach might include such basic steps as regularizing your routine and getting more exercise, along with prescribed medications, vitamins and supplements, counselling or therapy and social support. But the first step is diagnosis — and that can be somewhat complicated for PHAs.

## Risk factors

Research has shown that some things can make people vulnerable to depression or make depression worse. Health care professionals call these “risk factors.” They include:

- a history of depression before HIV diagnosis
- alcohol or substance (ab)use
- an anxiety disorder
- a family history in which a mother, father or sibling has any of the above
- a family history of suicide
- inadequate social support

The fact that PHAs may experience many stressful life events in a short period of time — related to social factors such as the difficulty of disclosing to others and the potential for rejection, the experience of stigma and discrimination as a result of HIV status, the loss of physical health and energy, and the deaths of friends and loved ones — can also increase the likelihood of depression.

# Aromatherapy blend

FOR DEPRESSION: A very uplifting blend.

For massage, mix the following essential oils in 25 ml of **grapeseed oil**:

**lavender** (6 drops) **grapefruit** (4 drops) **ylang ylang** (2 drops)

(optional: 1 drop of linden blossom or 1 drop of rose instead of ylang ylang)

Or simply add the essential oils to your bath.

Provided by Hazra, certified aromatherapist

## Brigitte Charbonneau, 56

*Diagnosed with HIV: 1994; CD4 count: 775; Viral load: undetectable. Vice-chair of Bruce House. Ottawa, Ontario*

I’ve been on so many meds. My worst experience was taking **ritonavir** [Norvir]. Besides major diarrhea and hair loss, I had severe depression, so severe that I considered suicide. I felt isolated, like nobody cared. I was on that drug for three months. With the meds I take now, I also feel depressed sometimes, which leads to tiredness, when all I want to do is sleep all the time. When I’m having a bad day, I don’t go anywhere, and this is hard for my grandchildren to understand. They notice that I take a lot of pills, and they know I do that to stay healthy.

More women need to come out and share how they feel. Maybe then, others can better understand what we’re going through. **ⓧ**

## Leahann, 22

*Diagnosed with HIV: 2000; CD4 count: 780; Viral load: undetectable. Receptionist at DEYAS (Downtown Eastside Youth Activities Society). Vancouver, BC*

My way of staying healthy is making sure that I come first, that I’m happy, and that I don’t settle for any less than I deserve. That may sound selfish, but it’s me, and it’s how I keep my spirits high. I think depression is valid in any person who is diagnosed with HIV. You feel crappy. I also felt crappy, but I started building a support network and seeing a counsellor. I didn’t want HIV to kill me; I wanted to kill HIV. I believe I’m the only person who can help me. I try not to let depression get to me. I keep myself educated on different issues around HIV and depression. I keep busy looking after others and my work helps me stay focused. **ⓧ**



## Symptoms

Psychotherapists and family physicians will typically look for the following symptoms in distinguishing between regular sorrow or worry and chronic depression:

- **A “down,” very low or irritable mood**, sometimes with outbursts of crying or anger triggered by minor incidents.
- **Not being able to take pleasure in activities of daily living**. Things that used to make you smile or distract you no longer give you joy.
- **Not caring about anything**. “What’s the point? I’m going to die anyway” becomes your response to a new challenge.
- **Appetite loss**, not attributable to a medical problem or drug side effect.
- **Difficulty falling or staying asleep**, not attributable to a prescribed or recreational drug.
- **Loss of sex drive**, not attributable to medication or HIV-related illness.
- **Fatigue**. Even getting out of bed or doing a tiny task has become difficult.
- **Difficulty concentrating or remembering things**. Tasks that you could do before without much thought now require all your attention to complete.
- **Difficulty making even small decisions**. You find yourself in the drugstore for a long time just trying to choose a new shampoo.
- **Feeling useless or worthless**, a global feeling like “everything I do is wrong.”
- **Social withdrawal**, removing yourself from family, friends or others whom you would normally see.
- **Thoughts of killing yourself**.

## Physical and other causes

PHAs can suffer from a host of HIV-related medical problems that mimic or overlap with many of these symptoms of depression. So a crucial first step is to identify — and treat — any physical causes. Talk with your doctor about getting tested for the following:

- anemia (can cause fatigue)
- sex hormone levels (hormone imbalances can diminish your sex drive)
- thyroid levels (women have a higher incidence of hypothyroidism, a common, treatable glandular disorder which can cause depression)
- HIV-related brain damage (can cause problems with memory and concentration)

Overall, the same diagnoses that apply to men also apply to women, but women can additionally have unique causes of depression. Physicians treating women should be careful to identify any relationship between depression and the following:

- menstruation
- pregnancy
- the perinatal period (around giving birth)
- the post-partum period (after giving birth)
- the perimenopausal period (around menopause)

Once you’ve taken steps to treat these physical problems, your doctor or therapist can better diagnose — and treat —

depression. Consider avoiding recreational drugs, alcohol and caffeine, which may disrupt your sleep cycle and cause fatigue.

Encourage your doctor to look into whether any of the medications you’re taking may be a factor, as a few can actually cause depression — or related symptoms, such as difficulty concentrating — in some people. Some meds known to cause depression or depression-like symptoms include:

- efavirenz (Sustiva, an antiretroviral)
- interferon (used to treat hepatitis C)
- acyclovir (Zovirax, used to treat herpes and shingles)
- co-trimoxazole (used for PCP prophylaxis)
- steroids (used to treat wasting)
- ethionamide (Trecator) and isoniazid (both used to treat TB)
- birth control pills or hormone replacement therapy
- muscle relaxants like Baclofen

Tell your doctor about all the meds you’re taking, so he or she can assess their relevance when diagnosing your depression.

## Testing

At this point, your health care provider may choose to use some standardized tests to help determine whether you are clinically depressed. One reliable tool is a brief multiple-choice questionnaire called the “Beck Depression Inventory.” Try not to be intimidated by these tests. Answer honestly, and the results can greatly help you and your caregiver plan your care and monitor your progress.

## Taking steps

If you and your physician or psychotherapist come to the conclusion that you are experiencing depression, here are some simple tips that may help you start to feel better:

- **Accept the fact that you may be depressed.** (You may already have while reading this article.)
- **Seek professional help.** Sometimes well-meaning friends will try to talk you out of your depression, without fully understanding the causes.
- **Break the cycle of depression by developing small goals** that you can gradually build on as you gain confidence and your mood improves. Try to:
  - Go to bed and wake up at the same time each day.
  - Wash your face, brush your teeth, comb your hair and get dressed each morning.
  - Get out of your home each day for a short walk or outing.
  - Engage in activities that you can stop or start easily, such as

light exercise or a shopping trip. (Exercise can release endorphins and adrenaline in your body that contribute to feelings of well-being, and a little retail therapy never hurts.)

- Choose a few friends or family members who are the easiest to be around and have short but frequent contacts with them.
- Avoid alcohol, recreational drugs and caffeine, as these have been shown to make depression worse in the long run. (A caution: If you're already taking an antidepressant, even mild use of alcohol or recreational drugs can substantially reduce the medicine's efficacy.)

## Counselling and therapy

Meeting with a professional trained to treat depression can help in a variety of ways:

- It can help you explore the reasons why you became depressed as well as the best ways to cope with your depression.
- It can help you minimize risk factors that might make your depression worse.
- It can provide a "sounding board" to help you regain feelings of control.

There are many kinds of therapy, from HIV support groups to one-on-one meetings with a psychotherapist. Therapists use different techniques to help you with your depression. Some use an expressive approach that helps you identify and vent your feelings. Others use an insight-oriented approach that helps you look at patterns of relationships over your life history and how they affect you today. Others focus more on problem-solving or behaviour change.

Cognitive/behavioural therapy (CBT) has the strongest data showing a benefit in decreasing symptoms of depression among PHAs. CBT is based on the premise that you largely feel the way that you think, so it's useful to become aware of underlying thought processes that may be making your depression worse. CBT helps you identify these thoughts and the situations that trigger them, so you and your therapist can then develop more reassuring thought patterns. This, in turn, will contribute to positive lifestyle changes. CBT does not try to turn you into a positive-thinking Pollyanna! Rather, it helps you acknowledge the legitimacy of the health threats and emotional struggles that you face, while allowing you to put them in context.

To find a psychotherapist, you can ask your family physician for a referral. You could also ask your HIV clinic or local AIDS organization whether they keep referral lists. Keep in mind that of the professions that typically do psychotherapy (psychiatry, psychology and social work), only psychiatrists may prescribe antidepressant medications. Ultimately, the most important thing is to choose a therapist whom you feel comfortable with and "click" with — if you feel you can only open up to a woman, trust your instincts. Make sure you pick someone who is willing to answer any of your questions without rushing you or being defensive.

**Remember:** If you're feeling suicidal, call your local crisis help-line or go immediately to the nearest emergency — don't wait for a therapy appointment!

## Antidepressants

Both the rate of depression and the severity of side effects of antidepressants may increase with the severity of HIV disease, but people may benefit from these drugs at any stage of disease. In certain circumstances, PHAs may be more sensitive to the effects of antidepressants and may therefore require lower dosing. Women may also require relatively lower doses of antidepressants than a man would, because of their relatively smaller body sizes, which may cause them to achieve higher levels of antidepressants in their blood. This particularly applies to women who may be underweight by virtue of their HIV disease. It should be noted that the potential effects of antidepressants on a fetus need to be considered when treating pregnant women, but there are some antidepressants that are considered safe for pregnant women.

The first-line antidepressants for PHAs — and the most commonly prescribed overall — are known as "selective serotonin uptake inhibitors" (SSRIs), a group that includes such drugs as Prozac, Zoloft, Paxil, Celexa and Luvox. SSRIs make available more of your body's natural serotonin, a neurotransmitter (signal-carrying chemical) that helps your body regulate mood — resulting in greater feelings of calm, well-being and happiness. Many PHAs swear by their SSRIs, but a few cautions: Some SSRIs cause side effects, including gastrointestinal upset and decreased sex drive, and some interact with HIV meds (for instance, the protease inhibitor ritonavir, or Norvir, increases the level of SSRIs in the blood). Check with your doctor or pharmacist about possible drug interactions. Some antidepressants, like Celexa, interact least with anti-HIV meds.

A second category of antidepressants, known as "tricyclics" (Norpramin, Elavil, Pamelor, Tofranil and Sinequan), are also used to treat chronic pain. A third category is known as MAO inhibitors. These are not commonly prescribed due to the large number of drug interactions and dietary restrictions. Other antidepressants with different chemical structures from SSRIs and tricyclics include Serzone, Remeron, Effexor, Wellbutrin and Bupropion.

Sometimes you may have to try more than one antidepressant before you find the right fit, so don't be discouraged. Antidepressants are non-addictive —

## Andrea Rudd, “over 40”

Diagnosed with HIV: 1988; CD4 count: 1,317; Viral load: undetectable. Artist. Works at various community-based organizations. Toronto, Ontario

I don't find having HIV inspiring at all. I find it totally depressing. Some people say it's the most empowering thing that ever happened to them. Well, not for me. It's a major drag that I try to cope with. I often feel like I'm being punished.

So, I try not to dwell on HIV. I enjoy things that have to do with relaxation and being in the moment. And human kindness. When it comes to just dealing with unpleasant things in the world, human kindness seems to always emerge.

A number of things help me cope. One is engaging in life. Another is the belief that there's some strong universal energy that's very powerful, that has its own momentum. That's a comforting thought – that one's personal miseries or difficulties are not really that big a deal in the grand scheme of things. 

## POST-PARTUM DEPRESSION

Post-partum depression (PPD) – depression after giving birth – does not present in the same way in every woman. Studies have shown that up to 80% of women experience a mild form of depression shortly after their baby is born, but a smaller percentage can experience more severe symptoms, which include:

- uncontrollable crying or persistent sadness
- feelings of anxiety or panic attacks
- restlessness and inability to sleep, despite exhaustion
- appetite loss
- irritability, moodiness
- a lack of interest in your child
- difficulty concentrating

It is quite common to feel extremely guilty if you are suffering from PPD, because everyone, including your husband or partner, is probably telling you that this should be a happy time. You can end up feeling like a bad mother for having some of these symptoms, but recognize that this is part of the illness. Don't self-diagnose or keep your feelings a secret because it may get much worse. Seek professional help; a good start is to talk with a trusted family doctor.

The exact cause of PPD is unknown, although some of the risk factors are similar to those already discussed in this article. Certainly, the issues associated with deciding whether to take antiretroviral therapy during pregnancy and the fears around your baby having HIV could contribute to PPD. Also, because so many HIV+ mothers are single parents or facing the prospects of single parenthood through death or abandonment, it is understandable how the new responsibilities that come with parenthood could be overwhelming.

Because PPD can be so serious, it is very important if you are pregnant or contemplating pregnancy to take preventive steps to ensure you have a good support network in place. Research shows that social support both from personal and professional sources can buffer you against many stresses that might otherwise result in depression.

unlike tranquilizers, such as Valium, which are highly addictive — and can be safely used for long periods of time. Many antidepressants decrease anxiety as well as depression, particularly important for many women with HIV. That IAPAC survey found that HIV doctors are more likely to prescribe antidepressants than any other intervention for depression, but keep this in mind: *Research has shown that antidepressants are most effective when combined with psychotherapy.*

If you're considering taking an antidepressant, make sure that your doctor knows about your HIV status, as well as any medications, supplements or herbal products that you're taking. This is because mixing some supplements, such as herbs, with antidepressants can cause dangerous side effects. If possible, see a specialist who knows how to best co-manage HIV disease and depression. 

David Coop, a trained psychotherapist with 14 years of experience in the HIV field, is the director of treatment information at CATIE. He holds Masters degrees in Counselling Psychology and Clinical Social Work. David is the former manager of the Immunodeficiency Clinic at Toronto General Hospital. He has two cats and loves to cook.

## Complementary Therapies

For more info on these supplements, go to [www.daair.org](http://www.daair.org).

**Omega-3 fatty acids:** Studies have shown that high doses of omega-3 fatty acids may reduce symptoms of depression – possibly by spiking serotonin levels. Salmon oil capsules are a good source of omega-3s.

**B-vitamin complex:** If your depression is related in part to vitamin deficiencies, adding this supplement to your diet can make a difference, particularly with anxiety. B<sub>6</sub> is particularly important for women.

**SAME:** European research finds that this nutrient (S-adenosyl-methionine, an amino acid derivative), important to brain and liver function, can have antidepressant effects – but so far, the data is slim.

**Bach Flower Remedies:** Many alternative health practitioners say that this tincture of essences from 38 flowering plants helps lift depression. It's nontoxic, but there's no data showing effectiveness.

**5HTP:** This is a form of the amino acid tryptophan, which your brain uses to make serotonin.

**Yoga, massage, meditation and mindfulness techniques:** These complementary therapies have shown some benefit in countering symptoms of mild depression.

**Acupuncture:** Two controlled studies have shown dramatic improvements in depression, plus relief from anxiety-related symptoms.

**WARNINGS:** **St. John's wort** used to be very popular with PHAs for treating depression. But it is now known that this herb interacts with many HIV meds – affecting the blood levels of several protease inhibitors and non-nukes as well as heart medicines – and therefore should be used with extreme caution and only after consultation with a licensed physician. **Kava** is also often taken for antidepressant and sedative effects. But this herb has been shown to cause severe liver toxicity. Health Canada recommends that it not be used.

# We've Come a Long Way, Baby

**MORE HIV+ WOMEN are realizing their dreams of becoming moms. With proper treatment and care, there's little reason baby shouldn't make three (or four...).**

*by Stacie Stukin and Lark Lands  
with nutrition tips by Diana Johansen*

WHEN KRISTINA GENOVY TURNED 18 MONTHS OLD, HER PARENTS GATHERED FAMILY AND FRIENDS TOGETHER FOR A JOYOUS DINNER to celebrate, laugh and have a good cry. Because her mother, Anne, is HIV+, Kristina had to take three HIV tests after she was born to make sure she didn't get the virus from her mom. The first two came back negative, but the third, administered at 18 months, was the defining result. Like the other tests, this one came back negative, proving the good news: Kristina was positively, no question, HIV negative.

It was a grueling 18 months for Anne. "I felt so guilty until the [third] test came back. I couldn't live with the thought of Kristina having what I have, because her life is so innocent." Anne's pregnancy was also a stressful journey. She found out she had HIV during a routine prenatal checkup and her doctor immediately booked an abortion. But Anne and her husband had other ideas. They wanted their baby and found an HIV specialist who gave them hope, along with a prescription for the anti-retroviral that would prevent transmission of the virus.

Kristina was born in 1996, just before the advent of HAART and the status of HIV as a potentially manageable chronic disease where good quality of life is not only possible but a right, at least in a country like Canada. Back then, the medical community, society and even HIV+ women themselves felt that they should not have babies. "There was a stigma," says Susan King, MD, co-director of the HIV/AIDS program at Toronto's Hospital for Sick Children.

We sure have come a long way, baby. According to Health Canada, the number of babies born to HIV+ moms increased from 56 in 1991 to 138 in 2001, and since 1996, the number of babies born with HIV has decreased. King says she now has HIV+ patients who are having second, even third babies. That's because today, with proper treatment, mother-to-child transmission can almost always be prevented. A great example: At Montreal's Sainte-Justine Hospital, the centre for mothers and children with AIDS boasts a transmission rate of zero.

In spite of these strides, deciding to have a baby is still a decision fraught with emotional, physical and social concerns. That's why King helped implement a counselling program at Toronto's Motherisk Clinic for HIV Treatment in Pregnancy as part of every positive mom-to-be's treatment strategy: "It's such a specialized area and we were finding that women weren't getting the most up-to-date information. We decided to create a place where they could come see what choices were available, have help looking at their options and eventually make the decision that's right for them."

Yvonne [not her real name], who didn't learn she was HIV+ until after the birth of her first baby, feels truly blessed that the child is negative. But before she and her husband (who also has HIV) decided to have their second child, she needed to know she had family support. She explained to her mother and siblings what could happen if she or the children got sick. "I needed my family's approval," Yvonne says. "If anything happened to me or my husband, I wanted to know they were up for the challenge and knew what they were in for." Yvonne just gave birth to her fourth HIV negative child. "I spend a lot of time with the kids," she says. "I'm lucky."

Both Anne and Yvonne will tell you that the day-to-day joys of motherhood help them cope with the anxieties of living with a chronic disease. "I love being a mom," Anne says. "It gives me a reason to live. Kristina makes my day. We call her Angel Bug and we feel like she's a gift from God."

## So you want to have a baby

Here are some things you should know:

**MTC TRANSMISSION** Mother-to-child transmission of HIV, also called perinatal or vertical transmission, can happen in 3 ways:

- HIV can pass to the fetus while in the womb through mom's blood supply. This is uncommon and usually only happens when mom's viral load is high.
- During labour and delivery, the baby can be infected by coming in close contact with mom's blood and bodily fluids in the birth canal. If mom's viral load is undetectable, her chances of transmitting the virus this way are greatly reduced.
- Breast milk carries HIV, so breast-feeding is a high-risk way to transmit the virus.

## Strategies to protect mom and baby

There are two very important components of treatment when a woman is pregnant. First and foremost, the health of the mother must be protected. Second, consideration should be given to preventing HIV transmission from the mother to the baby, and otherwise supporting the health of the baby. Alas, in focusing on the latter, the former is sometimes under-stressed. Deborah Money, MD, FRCSC, assistant professor and head of the Division of Maternal Fetal Medicine at the University of British Columbia, says, "We absolutely must focus primarily on the mother's health. The worst thing for a fetus is a critically ill mum."

In terms of HIV, the first thing to consider is whether the woman needs HAART for her own health. If she's already on an effective combination, she should stick with it. If she isn't on meds but the standard treatment guidelines indicate that she should be, then "they should be started immediately, even if it's early in the pregnancy," Dr. Money says. "The only caveat is that you pick the least toxic drugs. And, of course, avoid any drugs that might cause birth defects, including delavirdine (Rescriptor) and efavirenz (Sustiva)." She most commonly recommends a regimen containing the nukes AZT (it's tried and true and has been used for years in pregnant women with few problems) and 3TC (another long-used, non-problematic drug), combined with either the non-nuke nevirapine (Viramune) or the protease inhibitor nelfinavir (Viracept).

Standard treatment guidelines recommend doing genotyping (a blood test to look for drug resistance) with all pregnant women. However, in the treatment-naïve (those who've never been on HAART), Dr. Money and her colleagues tend to begin HAART without the test as a cost-saving measure, while storing the woman's blood to preserve the possibility of later testing if a failure to achieve a low viral load indicates the likelihood of drug resistance. In women who have previously taken HAART, genotyping is done before re-starting meds to increase the chances for picking an effective combination.

The mother should also be given any other therapies that are important to her health. For those with a CD4 count below 200, this would include prophylactic drugs to prevent opportunistic infections. "Don't avoid drugs because of fears," Dr. Money says. "You must protect mom first."

For expectant mothers whose viral loads and CD4 counts would not otherwise indicate a need for antiretrovirals (according to standard treatment guidelines), reducing the risk of MTC transmission is the key concern. Experts recommend that all pregnant HIV+ women begin HAART between 14 and 18 weeks into the pregnancy. "At that point, we start the woman on HAART and suppress her viral load to undetectable throughout the rest of the pregnancy, if possible," Dr. Money says.

There are two main reasons for this. First, although relatively rare overall, the possibility of HIV transmission in the womb goes up in synch with the mother's viral load. Second, there is always the possibility of a premature delivery. "In many HIV+ women, there are factors that increase the risk for pre-term delivery, including injection-drug or cocaine use, lack of access to care, and increased rates of sexually transmitted diseases," Dr. Money says. "So it's important to keep the viral load as low as possible through the last months of pregnancy to help prevent transmission during delivery." Even in women with undetectable viral loads, HAART has been shown to further reduce the risk of MTC transmission.

Blood tests to look for problems should be performed two weeks after starting antiretrovirals and then every month throughout the pregnancy. Also, it's very important that fetal growth and well-being be evaluated every four to six weeks until delivery.

When active labour begins (there is cervical dilation and/or contractions) or any time there is a ruptured membrane, doctors recommend that the mother continue taking her meds on schedule to the greatest extent possible (although nausea may prevent this). In addition, an AZT drip (intravenous) should be done throughout labour and delivery (with oral AZT discontinued). This helps prevent transmission by pre-loading the baby with AZT. For reasons that are unclear, this seems to work even when genotypic testing has shown that the mom is resistant to AZT, so the drip is recommended for all. After delivery, the AZT drip is stopped, and if the mom was only taking meds for the baby's sake, her HAART is stopped immediately. If she needs the meds for her own health, they're continued. The baby is given AZT syrup for the first six weeks of life.

In women who haven't taken HAART prior to going into labour, it's recommended that they be given a single dose of nevirapine (200 mg) as soon as possible after going into labour, that an AZT drip be given throughout labour, and that the baby be given a single dose of nevirapine immediately after birth, followed by six weeks of AZT syrup.

Clinicians used to believe that Cesarean section was the best way to reduce a newborn's exposure to mom's blood and bodily fluids. But a C-section is major surgery with multiple inherent risks, and experts now believe that if the mother's viral load is fully suppressed, there is no benefit to be gained from it. In a woman who has not been on HAART or whose viral load is not fully suppressed, a C-section can be considered at 38 weeks.

Last, but not least, just say no to breast-feeding. "It's quite clear the virus is in breast milk and even if mom has a low viral load, we suggest formula feeding," Dr. King explains. "It's safe and has nutritional benefits."

## Will HIV drugs hurt your baby?

Most HIV doctors, like Anita Rachlis, MD, medical director of the Ambulatory HIV Clinic at Sunnybrook and Women's College Health Sciences Centre in Toronto, agree that combination therapy is a must for HIV+ pregnant women but say that there are definite caveats. "Women considering pregnancy must discuss this with their treating physicians because certain drugs have the potential to cause malformations in the developing embryo."

For moms-to-be, the prospect of their children experiencing adverse reactions from HIV meds is a common fear. Because HAART has only been around since 1996, we don't really know its long-term effects. A French study of more than 4,000 women reported increased seizure disorders in infants exposed to HIV meds, but the seizures weren't life-threatening and affected only 30 babies. Additionally, researchers have speculated that HAART might negatively affect cellular energy, possibly harming organs like the brain and liver, but to date, research has not shown this. Research coordinator Johanne Samson, from Ste-Justine Hospital, says, "We're still concerned about the long-term effects and more research needs to be done."

Luckily, in December of 2001, the United States' Antiretroviral Pregnancy Registry released a study of 2,800 pregnancies that found that taking HIV meds during the first trimester did not increase the incidence of birth defects. For many women and clinicians, these results helped alleviate fears.

Dr. Money sums up the bottom line by saying: "Despite any remaining concerns, it should never be forgotten that the one thing we absolutely do know is that taking antiretrovirals very greatly reduces the risk of having an HIV+ baby, with all the lifetime risks and problems that creates. Any concerns about possible drug side effects must be put in that perspective."

## Caring for the whole woman

In addition to anything related to HIV, it should never be forgotten that mom-to-be needs all the things that any pregnant woman needs: good nutrition, supplementation with a prenatal vitamin/mineral formula, good prenatal care that includes being checked for diabetes and other possible complications, and so on. "There are a million and one standard pregnancy issues that need

to be taken care of," Dr. Money says. "Physicians should not get so focused on the HIV that they forget this is a pregnant woman with all the usual needs that are related to pregnancy in any woman."

For women not yet pregnant but planning to be, folic acid should be taken to prevent neural tube defects. During pregnancy, excellent nutrition is crucial for both mom and growing baby. In the 2<sup>nd</sup> and 3<sup>rd</sup> trimesters, it's important to add 300 calories and 15 extra grams of protein each day. Asking for a referral to a dietitian who can make recommendations on these and other dietary changes is an excellent idea for all moms-to-be. It is well known that the health of a newborn is influenced by the nutritional health of the mother throughout pregnancy.

Even without pregnancy, HIV infection is known to cause many nutrient deficiencies while increasing the need for calories, so it's even more important to optimize nutrient intake through both diet and prenatal supplements. The latter are higher in folic acid and iron and lower in vitamin A (which can cause birth defects in too-high doses). If you're considering taking other vitamins or complementary medicines, make sure they're safe during pregnancy. Check with your doctor, pharmacist and/or naturopathic physician.

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Diana Johansen, RD, is a clinical dietitian at the Oak Tree Clinic ([www.oaktreeclinic.bc.ca](http://www.oaktreeclinic.bc.ca)), a part of the Children's and Women's Health Centre of British Columbia. The clinic's Women and Family HIV Centre has clinical guidelines for the treatment of HIV+ women during labour and delivery and for the treatment of infants born to HIV+ women.

### A mother

*Diagnosed with HIV: 2000; CD4 count: 450; Viral load: 3,000. Montreal (Quebec)*

It's very important to have good health care, regular follow-ups and a good doctor you can talk to. A good, well-informed doctor is essential so you don't end up with misconceptions. Your doctor has to put you at ease and you must have good information.

I was pregnant with my second child when I was diagnosed with HIV. It was a shock, but I never thought my child would be infected because I took my meds and was told that if I followed the instructions carefully, my child would be OK. I never had any doubts about my child. My pregnancy wasn't any different from the first one. I had a C-section. I wanted to be sure that my doctor would be delivering the baby. I didn't want to have to deal with another doctor and have to tell my story. There was no problem.

I want to tell women with HIV not to give up when it comes to getting pregnant. The only problem is the treatment for the newborn. It was the most difficult time, six weeks of treatment with very frequent doctors' appointments. But besides that, everything is normal. We have to tell women to go forward, there's no reason not to.

# From Diapers to Disclosure

EXCERPTS FROM THE  
LIFE OF AN HIV+ MOTHER

by Shari Margolese

**We all know that living with HIV is a challenge.** Throw in motherhood, and life becomes a roller coaster. For the past decade, I've experienced the ups and downs of positive motherhood, from diapers to disclosure. Throughout this time, I've found support from many wonderful women, some who are no longer with us and others who continue to be my pillars of strength. All of these women have children and all of these women have stories. Mine is only one of them

## A pregnant pause

When I found out I was pregnant in 1992, HIV was the furthest thing from my mind. I was about to become a mom — in my case, a single suburban mom with a great career and supportive family. What was on my mind was preparing for the baby — making sure I had an appropriate place for us to live, stocking up on diapers and reading about “what to expect when you're expecting.” At nine months, I decided to upgrade my life insurance policy. The insurance company sent a nurse to my home to take blood and urine samples. When I asked what they were testing me for, she said, “I don't know, but they test for AIDS.” With that, she slapped an AIDS brochure on the coffee table and asked me to sign a consent form.

Later that month my son was born. The test never crossed my mind again until February 1993, when my mom and I were watching an AIDS documentary on TV. I said to my mom, “I haven't heard from the insurance company and they've cashed my deposit cheque, so I guess I don't have AIDS.”

March 13, 1993. I picked up the mail and there was a letter from the insurance company. It explained that, due to health reasons, they couldn't accept my application for life insurance. I was directed to contact my doctor in 10 days to find out why. I knew the news must have been bad, but not knowing exactly what it was, I called the insurance company and asked for my test information. Of course, they wouldn't give it to me. I asked them to fax it to my doctor's office and they finally agreed. When I spoke, by telephone, to the nurse in the office, she told me she'd received the fax and that I couldn't get insurance because I have HIV.

I had many emotions to deal with. I felt very guilty that my family would have to go through this. I felt confused and powerless. It was as though I'd lost complete control of my life. I was afraid: Afraid of what would happen to us. Afraid of what people would think. Afraid of notifying my previous partners. I was curious about how I was infected. I wondered if I would die. And I was angry. Angry with the doctor who had once told me that I wasn't in a high-risk group. And just plain angry.

These are many of the same emotions that other women have upon diagnosis. But I really couldn't take the time to deal with these emotions. I had to concentrate on the baby — who was now 3½ months old — and reduce his risk of transmission and get him diagnosed.

First, there was the process of switching him to a bottle, because I'd been nursing him. On the day of my diagnosis, I learned that HIV could be transmitted through breast milk, so I stopped nursing immediately. The next step was to get him diagnosed. At the HIV Clinic of the Toronto Hospital for Sick Children, I met with a highly skilled staff of doctors and nurses, dentists, psychologists and social workers. It was heartbreaking for me to see my tiny baby poked and prodded for blood.

Two months later, my son was diagnosed with HIV. When the doctor told me the news, I didn't ask too many questions. I didn't know what to ask. I think I was in shock.

## Mother's little helpers

MAY 1993 - Today was the worst day of my life. I found out the baby has it, too. I was so sure he wouldn't. I was so sure it couldn't get any worse. As soon as the doctor came in the room, I knew. He didn't even have to say a word. I couldn't help it, I started to cry. The baby laughed. It was almost as if he were saying, "Don't worry, mom."

The first few months after our diagnosis, the stress was overwhelming. I bordered on a nervous breakdown and left work on disability. I spent most of my time fussing over the baby and attending doctors' appointments for one or the other of us. During this time, a concerned family member brought me some resources about HIV. I started to research the disease I was facing. I realized that if we were going to survive I'd better pick myself up and find out as much about this virus as I possibly could. I contacted my local health department, which referred me to Voices of Positive Women. I attended my first support group about four months after my diagnosis. I couldn't believe the number of women there. Much of what they talked about went over my head and mostly I just sat there quietly and cried.

Later that summer, I attended the first camp for HIV+ moms and their kids, sponsored by Sick Kids Hospital. We moms met several times to discuss issues that we felt were important to us as parents. We all found the experience to be very rewarding and decided that we'd try to continue our newly found support group in some form. In the fall of 1993, the first support group for moms met in my grandmother's living room! Some women travelled up to 100 km to attend. With the assistance of Voices and The Teresa Group, our support group met once a month. We discussed such issues as who will care for our children if we get sick or die and how to talk to our kids about HIV.

Facilitating the moms' support group was very therapeutic for me. It allowed me to get support while volunteering my time and it made me feel like I was part of the solution. While I'm no longer involved as an active member of the moms' support group, it continues to thrive as a vibrant part of Voices' programming. In fact, similar programs are now available in other communities. Volunteerism and activism have become a very important part of my personal support and resource system.

## Mum's the word

NOVEMBER 1998 - There are days, most days, when it's like he doesn't even have it. He gets on the bus in the morning with all the other children, plays soccer before the bell and takes his seat with the rest of the class. At lunch he eats his sandwich and treat but leaves the apple for later. He goes to gym class, computer club and baseball practice - all the things that "normal" kids do. So, then, why isn't he treated normally? Why does he have to hide? Why do there have to be secrets? I thought it was OK to tell. I never thought people would still discriminate, especially not with a child. But I was wrong I was so wrong. And, believe me, that's hard for me to admit.

Disclosure is a very difficult and personal issue. I chose to disclose to my son naturally over time. As a positive child, he was used to taking medicine and seeing me take it. He was also used to going to the doctor's office. At about age 5, he began to ask questions like: "Why do I have to take medicine and my cousin doesn't?" and "Why do I have to get an IV and other kids don't?" I answered him in partial truths. At first, I told him he had special blood. Then, that he had a virus. He asked how he got it. That's when I told him he got it from me. Eventually he wanted to know the name of his virus. He now takes an active part in his own health care by sorting his medications and discussing symptoms and test results with his doctors.

While disclosing to kids is tough, asking them to keep a secret is tougher. There are times when I doubt my decision to tell him. It was heartbreaking to explain to my son that a lot of people don't know you can't get HIV from being friends and that they may be afraid to play with him.

Positive moms, whether or not their kids have HIV, often face stigma and fear discrimination for

themselves and their children while participating in regular family activities. Most parents don't tell schools and recreational clubs that they have HIV for fear of alienation. One school didn't want me to drive in a carpool because the principal was afraid I'd have an accident and bleed on the children. Clearly, this was discrimination, and I was furious. Unfortunately, it took a call from a lawyer for her to see the error of her ways. She later notified me that I was allowed to drive other students in my vehicle. However, this incident strained our relationship and made it uncomfortable for me to communicate with her about my son's progress in school. I didn't enroll him there the next year.

Another public school decided they'd begin using latex gloves to serve pizza on the day I was scheduled to volunteer for that task. As soon as the new rule was announced, I knew why and my heart sank. I could feel the tears well up in my eyes. Afterwards, I confronted the principal, who said that the health department had recommended the gloves and that it had nothing to do with me. I asked her if it was just a coincidence that they started doing it the day I was scheduled to volunteer. She didn't say a word. Again, the relationship became strained and uncomfortable. Several other discriminatory scenes took place at this school. Eventually I filed a human rights case against them, but it was unsuccessful. I felt it was necessary to change school districts and do what most parents do: not disclose.

Moms of HIV+ kids have added decisions around disclosure. Should I tell the babysitter, school or boy scouts? What about sports coaches? How do you handle medications for a sleepover? At first, I was afraid to leave my son with anyone who didn't know he has HIV, so most of the time I'd leave him only with family. I've since taught my son to keep his body fluids to himself and not to touch anyone else's. He only goes on sleepovers to friends and family who know he needs medication. As for schools, sports and scouts, sure, sometimes I'd like to tell, but I've realized that, for the most part, people really don't need to know and that, even in 2003, they often react poorly.

## Mother knows best

JUNE 2000 - I really didn't feel like walking him to school today. Not that I didn't want to, I just didn't feel like it.

Mothers with HIV, like most moms, tend to put their own needs second to the needs of their children. The kids need to be fed, the kids don't have clean clothes, the kids have swimming lessons, and so on. In addition, meeting with various doctors around the city about the health of one's HIV+ child leaves little time and energy for positive moms to do the same for themselves.

Sometimes I just don't feel well. For me, one of the hardest things about being an HIV+ mom is going on with your day and trying to act like all is OK when you really feel like you've been run over by a truck. There are days I don't want to make breakfast or lunch and walk to school. Although my son knows I have HIV, I don't want him to see me sick. I don't always hide how I feel, just enough so he doesn't worry too much.

When I decided to start HAART in the fall of 1996, I wasn't prepared for potential side effects. I experienced nausea and vomiting for several months, followed by kidney complications. With a 4 year old at home, I was run ragged. I seriously considered stopping the meds for a while so I could cook, clean and care for my son. Eventually I was able to get some help at home to get me through the roughest times.

Like all HIV+ women, I wrestle with treatment decisions for myself. In addition, I must consider choices for my son. One of the most difficult decisions I ever made was to give my child a medication that had previously sent me to the hospital with an adverse reaction. Such choices are further complicated by the small amount of research data available on which to base informed treatment decisions for women and children.

I've only begun to touch on the issues that HIV+ moms and their families face. Family life with HIV is a different experience for everyone. Various factors, including culture, relationships, geography and finances, compound our problems and affect our choices about disclosure, support, treatment and the future — choices not only for ourselves but also for our children. As a positive mom, I've faced a myriad of daily challenges, but they're very often rewarded with a simple "Thanks mom, you're the best!" ...and that makes the struggle more than worthwhile. 



Shari Margolese has been an active voice for women and HIV for 10 years. As the National Women's Representative of the Canadian Treatment Action Council (CTAC), she advocates for access to appropriate and timely treatment for women with HIV. Shari was recently awarded The Golden Jubilee Medal of Queen Elizabeth II for significant contribution to her community. For more info about Shari and CTAC, go to [www.ctac.ca](http://www.ctac.ca).

Photo: Jake Peters

## Robyn, 33

*Diagnosed with HIV: 1993; CD4 count: 680; Viral load: undetectable. Homemaker. St. John's, Newfoundland*

I have two children, 9 and 12, and they know about my status. They were fairly young when I introduced them to this idea, on their own level, and as they got older I geared any information to age appropriateness. They don't see this as a death sentence — I wouldn't allow for these thoughts — just a chronic condition, when mommy has to take care of herself. My son is now coming to deal with the stress about his own mortality, and his father's and mine, and he's afraid but we're dealing with it. Both my kids are healthy and great.

I used to volunteer a lot, and from time to time I still do. When I started, my son was just a baby and there was no childcare at the AIDS committee, so I had to take him with me and he'd sleep in the playpen. I've done public speaking, but I kind of burned out, and I needed to take more time for myself. The kids aren't old enough yet to stay at home alone, and I don't mind doing something now and again, but I want to spend my time with them. They're the focus of my life, even though they sometimes drive me nuts.

As a single mom, to get rid of the stresses of the day, I listen to relaxation tapes, take walks with my kids, play darts — that's a stress reliever! When you have kids, you try to gear everything toward them. I also take long baths and listen to sounds of nature. I try to maintain a positive attitude and be an optimist. I guess your mind has to be in some state of denial in order to cope. On my good days, I make the most of it; on my not-so-good days, I tend to be a hypochondriac. But I really try to not let things get me down and to take every day as it comes. Life isn't bad; it's only what you make of it. ♂

## Nicole Hicks, 34

*Diagnosed with HIV: 1992; CD4 count: 505; Viral load: 1,800. Peer mentor at Voices of Positive Women. Education outreach worker at Algoma AIDS Network. Sault Ste. Marie, Ontario*

There's a need to ensure that women's voices are heard. We need to address some barriers, such as access to childcare. In order for people to participate and be active, their needs have to be taken care of. Caregiving is a big issue for women. There seems to be a lack of support in communities for families dealing with HIV.



My children are very important to me, but being a mother of four is very tiresome. At the end of the day, I go home from work and do the groceries, cleaning, kids' homework. It's a never ending situation. Even though my partner helps me, he's limited in what he can physically do.

It's very difficult for children to know what situation their parents are facing. My oldest daughter, 16, helps me out a lot. She feels a lot of pressure. This may be one reason why our kids put themselves at risk more — the stress and feeling that they have to fill the parental role. So they look for the release mechanism with sex, drugs and alcohol. Quite often my daughter puts herself in risky positions. It's hard to sit back and see her do that. I try to make myself open to her so she can talk about anything, and she feels very comfortable discussing things with me. Initiating safer sex/alcohol/drug conversations can be a huge issue, but leaving it for the heat of the moment only makes it more difficult.

There's no support for children like my daughter. My kids don't get to enjoy the benefits of ballet or sports because of the high expenses associated with these activities. Finding economical things for them to do is difficult. They've fought with depression quite a bit. When I'm ill, for them it all comes back to the question: "What's going to happen to us?" There's no program to address their concerns, no mechanisms or plans built in for future care of the kids. Right now there are no options for my children, there are no family members who could fill that parental role. ♂

## Rhonda Stevens, 32

*Diagnosed with HIV: 1994; CD4 count: around 300; Viral load: undetectable. Peer educator at various AIDS organizations. Toronto, Ontario*

I'm a single mother living with HIV, with three children and no other family in Toronto. My family is in the Caribbean and the U.S.; I wish they were around. It's very hard at times, especially now, because my 12-year-old daughter is having some teenage problems. She's also HIV+. My other kids know that my eldest girl and I both have HIV. I've always been really open and honest with them. I had a girlfriend, she's still living with me but we're not getting along, and I think that's contributing to my daughter's actions right now. ♂



Photos: Jake Peters

## Sylvie Olivier, 34

*Diagnosed with HIV: 1989; CD4 count: 1,024; Viral load: around 50. Volunteer at various AIDS organizations, including Voices of Positive Women, Kingston AIDS Project and Street Health. Artist. Kingston, Ontario*

Being a mother means a lot to me. I thought I'd never have children. Before I tested positive, I went for a fertility test. After my doctor learned that I used drugs and was involved in sex work, she suggested an HIV test. I'd just moved from Montreal and didn't speak English well, so when I came to pick up the result she told me I was positive and I thought it was good and asked her when I should make another appointment. Then she took out a box of Kleenex and said: "You don't understand. You have AIDS." I gave up my dreams of having children.

Now I'm the mother of a healthy 3-year-old boy! He helps me stay happy. I get us involved in different educational programs and sports activities. I look around the community and see what's out there. When you volunteer for an organization, they usually give you some incentives, which makes life a bit easier. It's nice because you're not always stuck at home. When your child is first born, it's great! But after a year and a half, I wanted to get out of the house. Now I make sure my son has different opportunities to meet and play with other kids. And I get to meet other adults. The organizations I volunteer at usually provide childcare and help me have time for myself. That really helps. So, when there's an agency that interests you, call and ask how you can get involved. ♂

# Sex, Drugs & HIV

**Drug users are  
CITIZENS like any other!**



*by Chantale Perron*

**N**OVEMBER 2002 MARKED EIGHT YEARS OF A HEROIN-FREE LIFE. I travelled a long road to stop taking the drug that was destroying my health and making me unhappy. I've been living with HIV and hepatitis C since 1992. My name is Chantale Perron and I'm 36 years old.

It took me two years to get over my diagnosis. I thought my life was over, with no hope of ever having a boyfriend, job or children. But, eventually, I started to work on myself, improving my self-esteem and affirmation skills (I learned to say no instead of yes all the time, I started to speak my real thoughts and defend my opinion). I'd always been very weak, especially when it came to men. I tried to please them all the time, because I thought that no man would want to be with a girl like me (even before HIV, so imagine how I felt after!).

Those days are behind me now. I have a boyfriend of six years and we are very much in love. He was also an injection drug user (IDU). And he has HIV, too, so we have that in common...and much more.

For the past few years, I've worked at CPAVIH (Comité des Personnes Atteintes du VIH du Québec), mostly providing information about the medical aspects of HIV. Because of my personal experience with drugs and HIV, I'm often invited to conferences and to sit on committees as a representative of drug users and PHAs, to make sure that good decisions are made regarding the real needs of these people. I like to be able to help people who use drugs. Maybe it's because I know too well all the obstacles that they have to go through, all the judgments and misconceptions they have to fight.

What keeps me going? Defending a cause and feeling useful. That's why I've devoted my life to ensuring that the harm reduction approach is adopted, in order to improve the lives of drug users in Canada. In 2001, I

created *Pusher d'Infos*, a journal written primarily by and for current and former users, in order to give a voice to drug users and provide a space where they can express themselves and defend their rights. The journal provides information to educate users so they don't get HIV and hepatitis, as well as information that helps those with HIV and hepatitis feel better. Drug users are involved in the project every step of the way and they get paid like everyone else. *Pusher d'Infos* has been extremely popular and well-received in Quebec (99% of content is in French with an occasional article or poem in English). We have many more ideas, just watch us!

## WHAT IS HARM REDUCTION?

**T**he "official" definition of harm reduction is described as "a pragmatic approach that focuses on reducing the harmful consequences of drug use rather than on its elimination." In other words, since the war on drugs and its many sanctions clearly do not prevent people from using illegal drugs, why not give users the means to protect their health as well as that of others? With this approach, the needs of the person (ie. the drug user) are taken care of first.

That's what I like about it. Forget about the typical drug-user profile and the infallible method that will help all users abstain — they don't exist. However, by treating drug users as human beings and attempting to meet their needs and offer them options, we can obtain concrete results, such as reducing the spread of HIV and hepatitis C as well as helping users who have these diseases to live longer, healthy lives.

## HARM REDUCTION CAN CHANGE THE WORLD

**H**arm reduction can take many forms. Needle exchanges are great, but harm reduction has to go further than that. More choices and tools should be made available so each user can find the method that suits him or her best. We also need services or approaches that fit better with women's realities. I've noticed that in therapy centres there are more men than women; the same is true at CPAVIH and with *Pusher d'Infos*. For some reason, it's more difficult to reach women. But women using drugs and/or who have HIV are out there, with different needs than men, surviving in a different way than men do.

I know that most women prefer to be guided, not confronted. If a woman needs help to (re)gain her self-esteem, she doesn't need to be broken in order to get reconstructed (as is often done in some therapy and rehab centres). I was in that situation, broken and disillusioned, when Louise, a social worker, found me. Others had given up on me because I'd relapsed too many times. But Louise gave me hope that some day I could be happy again. She also gave me a lot of practical info that I could use. Even though my goal was to stop using drugs someday, Louise taught me about safe injection (and safe sex, of course!).

## SEX AND DRUG USERS: WE STILL DO IT!

**O**ver the years, I've observed that messages about safe injection have had a positive effect on the habits of users. Most know that sharing needles carries a high risk of HIV and hep C infection, and most are careful. But when it comes to intimacy, drug users are like anyone else: They think condoms are for other people. The safe-sex aspect of prevention is too often overlooked in info targeted at users. Shooting up doesn't stop someone from having a sex life...on the contrary!

## THE WAR AGAINST HIV AND HEP C

**I**'m now one of many statistics about HIV and hepatitis C co-infection among IDUs. Fortunately, the HIV epidemic and the wave of hep C infections that continues to follow it have at least alerted the authorities. As a result, more money is now being invested into the health of drug users. In order to reach this population, the door had to be opened to new ideas. Bold projects have been put in place and the situation in Canada is slowly beginning to improve. It's about time.

## ME AND MY METHADONE

**M**y methadone story illustrates both the remarkable results that can be obtained from this approach as well as the urgent need to act quickly to help those who seek this form of aid.

Methadone is a synthetic narcotic painkiller that produces many of the same effects as heroin or morphine, only it doesn't get you high. It allows a person who is heroin-dependent to get

### Sylvie Olivier, 34

*Diagnosed with HIV: 1989; CD4 count: 1,024; Viral load: around 50. Volunteer at various AIDS organizations, including Voices of Positive Women, Kingston AIDS Project and Street Health. Artist. Kingston, Ontario*

**F**or seven years I lived in an abusive relationship. I left in 1995, when I realized my partner was never going to change. He never helped me and only made me feel worse. If you're in a bad relationship, first of all find someone you can talk about it with. Go to your best girlfriend and don't tell anyone else about it. Go to a shelter. Sometimes you may need to relocate, so be ready for it. Sometimes hearing from others in a similar situation might help. This is what I did for myself. And after seven years in misery, I was able to meet someone else, withdraw from drugs and have a healthy child. Being on methadone has helped me. I've been on it since April 2001. It doesn't interfere with my meds, and it hasn't caused me any problems yet. It helps me deal with my mood swings and feel more stable.

Things are looking good for me now. It was a great bonus to learn that my child is negative. 



### Cindy Reardon, 34

*Diagnosed with HIV: April 1995; CD4 count: 1,324; Viral load: 167. Harm reduction worker. Toronto, Ontario*

**S**ome women with HIV are more vulnerable than others because they have a "drug user" label on their medical file. So when the time comes for pain medication, they're not properly treated. I want to make sure that I'm honest with my doctor if I'm doing drugs recreationally, just like I would be if I was drinking alcohol. We have to educate doctors about drug interactions, and we have to empower women and make them as safe as possible while they're using drugs and taking HIV meds.

There's more info out there for men and more of the larger agencies cater to men. I'm a lesbian, and my issues are not all the same as those of heterosexual women (and after seven years of living with HIV, my issues are different than they were when I was first diagnosed). There is some info out there, but very few support groups for women like me. 



Photo: Jake Peters

For 4 free issues/year of *Pusher d'Infos*  
phone: 514.529.8008 e-mail: [jlemonde@colba.net](mailto:jlemonde@colba.net).

**The Canadian Harm Reduction Network**  
toll-free: 1.800.728.1293 [www.canadianharmreduction.com](http://www.canadianharmreduction.com)

The **Harm Reduction Coalition** [www.harmreduction.org](http://www.harmreduction.org)  
*Junkphood* [www.needleexchange.com/junkphood/](http://www.needleexchange.com/junkphood/)

**VANDU** (Vancouver Area Network of Drug Users)  
phone: 604.683.8595 [www.vandu.org](http://www.vandu.org)

**IDUUT** (Illicit Drug Users Union of Toronto)  
phone: 416.920.2746 e-mail: [iduut@rogers.com](mailto:iduut@rogers.com)

Canadian Harm Reduction Conference [www.harmreduction2002.ca](http://www.harmreduction2002.ca)

Check out *pre\*fix*, CATIE's new harm reduction booklet for HIV+ users!

through the day without having to do illegal drugs and without being dope-sick because they need more. Methadone lasts longer than heroin, for up to 24 hours, and people can drink it once a day, every day, instead of having to shoot heroin every eight hours in order to not get sick (to not have the symptoms of withdrawal after 8-12 hours, because drugs like heroin create a physical dependence). Methadone is legal but has to be prescribed.

After injecting heroin for several years, I wanted to change my life. Easier said than done! My entire life had been transformed by the drug — my thoughts, activities, needs. Everything revolved around the next hit and the fear of not having it. I tried several methods to quit. I underwent three detox treatments at the hospital, complete with drugs to ease the pain of withdrawal. I spent time in treatment centres that promoted the cold-turkey approach, but I relapsed each time I left. Short-term therapies also failed, and an 18-month treatment program had no better result.

When my outreach worker suggested I try a methadone program, I had pretty much lost faith. Still, I registered for it anyway. At the time, money was scarce and the number of places was limited. The waiting list was two years long. The eligibility criteria were such that pregnant women and HIV+ women were admitted first. I was neither pregnant nor positive, so I added my name to the list and waited. Obviously, I continued to do heroin during that time because I was unable to stop.

Two years later, it was finally my turn. By then, however, it was as a woman infected with both HIV and hep C that I entered the methadone program.

I am no doubt one of many to whom that happened, but fortunately things have improved. In Quebec, for example, funding has been secured and the number of places available in methadone programs has increased. There are also alternatives available now, such as low-level methadone substitution and an outpatient detox program.

Although it doesn't give me the buzz that dope did, my daily methadone treatment spares me from the agony of withdrawal and the defeat of repeated relapses. As a result, I haven't injected drugs in eight years, which is a miracle for someone whom several doctors had described as "beyond hope." My experience hasn't left me bitter. But I continue to fight so no one else has to go through what I did. And I continue to take my daily bottle of 75 mg of methadone, along with my HIV medications, which I've taken since 1996.

Methadone can interact with some HIV meds and other meds (such as antifungals), including:

- nelfinavir (Viracept)
- lopinavir (Kaletra)
- nevirapine (Viramune)
- abacavir (Ziagen)
- ketoconazole (Nizoral)
- ritonavir (Norvir)
- efavirenz (Sustiva)
- delavirdine (Rescriptor)
- fluconazole (Diflucan)
- rifampin

When you take methadone and one or more of these meds, methadone levels in your blood may either increase or decrease

(causing symptoms of withdrawal). So, you need to be vigilant and watch if you start to have withdrawal symptoms. This tends to happen slowly, usually within two weeks of starting these meds. In some cases, your methadone dose may need to be adjusted.

Your doctor and pharmacist should know these things. But, you have to tell them about *all* the drugs you're taking if you want them to help you. The same goes with your doctor when it's time to talk about street or recreational drugs. For instance, if your HIV treatment includes ritonavir and doc doesn't know that you do ecstasy every weekend, he or she won't be able to tell you that ritonavir has a tendency to increase the level of any drug (legal or not, your body doesn't bother with the laws).

## DRUGS AND VIOLENCE

When you do hard drugs, you enter another world. All facets of your life are altered. The fact that drugs are illegal has a lot to do with that. It's a jungle out there and everyone's fighting for his or her own piece of fake paradise. You have to hide, lie and search for money constantly. In the end, it changes you.

Like many other women, I became dependent on a man who, in exchange for a roof and a bit of dope, abused me both physically and verbally. It's not easy to help women in such a situation. It takes a great amount of courage and help to quit a guy. Most of the time, there are other considerations (if you leave, will you have to do sex work to afford to live? Do you have children who will go hungry? Will he threaten you?). It's not easy to get out of these situations, especially if love is involved. It could take more than a few times before you succeed. Women should not be afraid to ask for help, even if it's the tenth time they do. There is no guilt to be felt. If the person who is supposed to be helping you can't understand that, try to seek help somewhere else.

## CITIZENS LIKE ANY OTHER

The lights came on for me when I learned that drug users in Australia and France had formed groups to defend their rights. I could hardly believe it! That's how I came to believe in harm reduction. People who use drugs are, above all, human beings and citizens like any other and deserve respect. That's why users have to become involved and must be present when decisions are made. ♂

# The Golden YEARS

**ANA IS A 77-YEAR-OLD GRANDMOTHER. She bakes cakes, makes clothes for teddy bears and volunteers at her Montreal AIDS community group because, like the people she meets there, Ana is living with HIV.**

*by Tracy Barber*

**Q: How is your health, Ana?**

**A:** It's good. My CD4 count is above 400 and my viral load is undetectable. I've done great for the past nine years. Naturally, from time to time I feel down. But I'm doing better than many young people. I think it has to do with my genes and my attitude. I'm optimistic, no matter what.

**How did you learn you had HIV?**

My husband was in the hospital in 1993, very sick with pneumonia. Dr. Ian Mackay, an AIDS specialist, was on call in the intensive care unit. When he looked at my husband's chart, he had the idea my husband might have AIDS. I gave permission for the test. It was positive. My husband had had a blood transfusion during major surgery in 1985. But back then he didn't have any symptoms of HIV infection. At our age, no one was even thinking about it. He also had emphysema. Really, he died of lung cancer.

**So after he tested positive, they tested you?**

Yes. In a way I knew: We were husband and wife. We had a healthy marriage.

**What was it like after you were diagnosed?**

It was hard for my husband. He was really depressed. Dr. Mackay was very good to us. He came every night to talk to my husband. I'll never forget that. He also helped me get over the shock.

**It sounds like you have a good relationship with him.**

Dr. Mackay is my friend. So is my regular doctor, Dr. McLeod.

**How often do you see your regular doctor?**

Once a month, sometimes more. Together with the nurses we're a team. My job is to come for checkups and blood tests and to take my medication regularly, exactly as the doctor prescribes. You must listen to what your doctor says. And always ask questions.

Recently my doctor asked me to meet with a group of first-year medical students, to see if they could make a correct diagnosis. They examined me and asked me questions.

**Did they diagnose you correctly?**

Not really, but that wasn't important. At the end, many of them thanked me for participating. They'll be studying my case for 18 months. I want to do what I can to help.

**Do you have any particular health problems now?**

I had some problems with my breasts; it was a side effect of a medication I was taking. But we've changed that one, so I'm much better now.

**Do you use any complementary therapies?**

Yes, a few, including one for my arthritis, which is really helping me. I also take vitamin E, for my breasts. My doctor makes sure these don't interfere with the medicines I'm taking.

**Do you attend any support groups?**

Yes, I'm good at baking so I bring cake. And I'm good at listening. The other people trust me and tell me what's in their heart and soul. This way, I'm giving back what I've received. I'm very thankful to God that he gave me such a good way to help people. I never judge. I never ask questions that could hurt them. I know God loves me. It helps a lot to have religion and beliefs.

**Do the people at your church know you have HIV?**

No, acceptance is still far away. I tell who I want to tell; that's my privilege.

**Have you ever met anyone like yourself in the AIDS community?**

Yes and no. I'm always the oldest one, but I don't care. I am part of them. I understand them, and they respect and care for me. I met two young African women who are just like me: strong, hard-working women, with great love for their families. I grew up in Europe, decades before these women were even born, and yet we love each other like sisters raised by the same good mother. We have such beautiful talks together. Women must share their strength and support each other.

**What inspires you?**

My family's love and acceptance. We were together when I learned I had HIV and we've been together ever since. And volunteering in the AIDS community makes me happy and gives me hope. I can be "grandmother" to people who need family love. My doctor says I will probably die of old age — that makes me live. ♂

# Yoursself

by  
Rebekka Valian

**Looking back on my health, I'm sure I contracted HIV in 1990, but it wasn't confirmed until 1992,** when Larry, my boyfriend of two years, was diagnosed with AIDS. Two months later, I tested positive. From day one, I tried to cultivate a positive attitude about my life with HIV. In an effort to keep myself grounded and calm and not get too psyched out, I kept my diagnosis under wraps for a while because I didn't want other people's reactions and fears to affect me. I tried a bunch of alternative therapies such as acupuncture and herbs — some didn't work for me but those that did I continue to use today. I thought if I could keep my mind, body and spirit in synch, my health would remain stable. My CD4 count was quite high in those days. Larry, however, upon diagnosis had full-blown AIDS.

As Larry's health declined, he made preparations to die and made peace where necessary. He passed away on August 14, 1994, with me by his side. I was so proud of him. He made death look easy. After we said goodbye, Larry took his last breath. All his energy was sucked inward, as if his spirit completely entered his body on his last breath, flew down to his feet, turned and shot up and out through the crown of his head. My heart was pounding and my body shaking as I held his hand. I was in complete awe of the beauty of this moment. I felt the light in the room, and now that I've since assisted in the birth of my goddess-daughter, I have to say, the energy in the room when Larry died was very similar — sacred and beautiful — to the energy I felt at the birth. I share this experience because it was extremely empowering to me. Larry taught me not to fear death.

I've been living with the virus now for 13 years. Complementary therapies such as massage, acupuncture, Traditional Chinese Medicine, herbs, yoga, meditation and visualization help me to rejuvenate and stay optimistic about my health. For a long time I was reluctant to take HIV drugs because I had a bias against Western medicine, especially after having watched Larry suffer from the effects of high-dose AZT that was commonly prescribed in the early 1990s. But four years ago I added a drug cocktail to my therapies. At 30 CD4 cells, my immune system had become so depleted and I'd developed the opportunistic infection MAC. So I finally backed down and decided to believe my doctor when she told me I didn't have long >

*continued on page 46*

## TREE OF LIFE

**P**art of living in balance is feeling one's connection to nature, to the Universe and to other people. Notice your connection with the world around you and don't miss the synchronicity of events in your day. This is one way the Universe speaks to us.

If you can't be in nature, bring nature to yourself by closing your eyes and visualizing or feeling yourself walking in the woods or along the water's edge. Your body can still reap the benefits of actually being there. Breathe deeply and let serenity reign.

You need only 5 minutes to do this. Designate a time and space for yourself (even if it means locking yourself in the washroom). Sit in a comfortable position that allows your spine to be erect. Gently close your eyes. See or sense yourself sitting under a magnificent tree. You chose the details (oak, maple, willow, palm). Inhale and exhale through your nose, both to a count of 4. On each inhale, fill your belly up like a big balloon, up to your chest, up to your shoulders, to a count of 4. Exhale slowly to 4, contracting your belly toward your spine, releasing every last drop of breath.

As you inhale, breathe in clean, life-supporting oxygen, produced by the tree. See a line of connection from the tree to your lungs. When you exhale, you are expelling toxins from your body. The carbon dioxide you release is food that's essential to the tree. See a line of energy back to the tree. A symbiotic relationship exists. We are deeply connected and dependent on each other for existence. Feel your connection. Repeat this visualization for 5 to 10 minutes until you feel relaxed and grounded. You can use this simple exercise any time to relax.

## Hazra, 46

*Diagnosed with HIV: 1994; CD4 count: 1,100; Viral load: undetectable. Aromatherapist. Reflexologist. Reiki practitioner. Student. York Region, Ontario*

**E**very morning when I wake up, I deal with exhaustion. So I do Reiki, bringing the universal energy to myself. It's the best self-help method I know. After Reiki, I do aromatherapy — blending essential oils according to my mood and physical condition — and massage myself. The oils help me when I have nausea, diarrhea, depression. After the massage, I go about my day feeling really good.

Each morning I design a very reasonable schedule for myself, so at the end of the day I've been able to do everything I planned. This brings me a feeling of satisfaction. I do various things to keep my body moving, such as belly dancing and Qi Gong. I like the belly dancing, it's not only exercise but also fun. This in itself creates a feeling of well-being. I also get regular treatments (massage, reflexology, trager, shiatsu, Reiki) from other practitioners. My personal belief is that there is a physical aspect to any disease, but there's also a psychosomatic aspect to it, and it's important to work with every aspect for self-healing. To me, psychotherapy has become more of a spiritual journey and has helped me bring changes to my life and relationships. ✂

Taking time out for you is one of the best things you can do

## Andrea Rudd, "over 40"

*Diagnosed with HIV: 1988; CD4 count: 1,317; Viral load: undetectable. Artist. Works at various community-based organizations. Toronto, Ontario*

**H**aving experienced an extended period of time when I slept no more than an hour or two per night, sleep is something that I hold in high esteem. I had a terrible time when I started taking antiretrovirals; I couldn't sleep at all for a few months. When you can't sleep, you can't cope, your sense of reality gets totally distorted. For one or two days you can go without sleep, but after three months, it's just insane. You go mad.

What changed that state is that I went to a naturopathic doctor, Ken Luby, and he gave me one homeopathic remedy, which totally shifted the cycle I was in. I only took one dose, and from that moment on I was able to sleep again. It was very, very powerful. My whole life changed. Ken Luby is my hero. He was profoundly helpful.

Ever since then, having a good night's sleep has become a priority for me. I do Feldenkrais exercises before I go to bed. They're very slow movements which totally bring things into the moment by relaxing and slowing down your whole being. They're grounding and centering. You don't have to exert much energy to do them, so they're easy to do at night when you're tired. I've always done exercise and body work because they take you out of your head and bring you into the moment. I find that both useful and meaningful — getting out of my thoughts and into the moment. ✂

# 8 *Rebekka's* steps to de-stress

## **Drink lots of water (8 glasses a day).**

If your CD4 count is below 200, try to purchase water that uses reverse osmosis to filter cryptosporidium and giardia (read the labels). Our bodies are made up of 75% to 90% water, and water flushes out toxins from the body and hydrates every living cell.

## **Eat living foods** (fresh fruits and greens, whole grains, soy products, juicing).

Sense the vibratory energy of your food. Observe the visible life of a fresh green salad vs. over-processed, overcooked food. Avoid the processed-food aisles in your grocery store as much as possible. Check that the life hasn't been processed out of your food...again, read the labels!

## **Slow down and savour the moment.**

Be mindful and present. Rest and relax. Get a massage to boost your body's circulation and immune system.

## **Trust yourself.**

Listen to your inner voice. Keep a journal. Dare to fulfill a dream. Learn the power of intent. Put out a wish or prayer and don't be surprised if you get what you ask for. Remember to give thanks.

## **Rejoice.**

Celebrate in a favourite activity. Try Indian tablas or African or Native drumming. Studies show that you can boost your white blood cell count when you drum.

## **Exercise.**

Get your heart pumping and blood circulating. And don't forget to breathe! You're flushing out toxins and boosting your immune system. Walk, swim, dance, cycle...pick your favourite. Not only will it benefit you physically, it will also lift your spirits. Sex counts as exercise!

## **Speak sweetly to yourself.**

Your words to yourself can either heal or harm you. Speaking and thinking positive thoughts raises the vibration within you and your environment. Psyche yourself up. Every cell in your body will respond. Each of us is unique and holds different gifts and perspectives. Respect yourself.

## **Seek out help.**

Utilize your AIDS organizations. They may have resources or programs that make your life easier. Opportunities may exist that you are unaware of. Connect with others. If you live in a remote area, reach out and access e-mail or toll-free numbers. Communicating with other women with similar issues is an invaluable resource of support and information. Accept support from family and friends. Celebrate your relationships.

> continued from page 44

to live. Although today my health is good (600 CD4 cells and an undetectable viral load), I'm experiencing side effects from my medication, most notably lipodystrophy. My legs and face are thinning while my waist is thickening. Seeing these changes in my figure is frustrating and it's an effort to keep my vanity in check.

Practicing yoga has helped me to survive in more ways than one. The word *yoga* means "to yoke" or "union." It's about uniting the body, mind and spirit in order to improve health and increase self-awareness. This yoking also refers to the union of the individual's consciousness with the larger infinite consciousness. The postures, which are synchronized with the breath, allow you to check in deeply with your body and quiet your busy mind. On a physiological level, yoga improves blood circulation, respiration, digestion, liver detoxification and lymphatic drainage. You're building your immune system when you do yoga. It's also helped melt away a few inches and, thankfully, helps to alleviate depression as well.

When a person is depressed, we sometimes use expressions like "heavy-hearted" or "disheartened" to describe this unpleasant state. Depression can be a reaction to too much stress. Literally, depression stresses the heart and body and overactivates the adrenal system. When practicing yoga, your flow of stretches and breathing techniques becomes a moving meditation in which the body is able to deeply relax. The body's autonomic nervous system switches into the parasympathetic mode, giving every cell much needed rest. As a result, the mind and body quiet, and a beautiful stillness comes over you in which deep healing can occur. You feel a sense of calm and, with regular practice, the heaviness of depression often disperses. (For more info on yoga for PHAs, see "Introduction to Yoga," *The Positive Side*, fall/winter 2001.)

Stress is an inhibitor to health. When one's immune system is compromised, it is essential to de-stress in as many ways as possible. Presently, for me, this means not working and using this time to return to health. I'm learning to live in balance, creating space and time away from my busy life to nourish and recharge myself. Having the courage to say "no" at times and simplify my life is essential for the restoration of my immune system.

Contracting HIV has been an invitation for me to slow down, be more mindful and savour the moment. Every activity is more enjoyable when I take time to really stay present and experience what I'm doing — whether it's practicing yoga or cooking dinner. I encourage you to allow yourself some down-time to meditate, take a walk in nature, do yoga, receive a massage or take a nap (in a hammock, if you can!).



Rebekka Valian is a member of Positive Women's Network ([www.pwn.bc.ca](http://www.pwn.bc.ca)) in Vancouver, where she volunteers as a reflexologist, aromatherapist and yoga teacher. She also teaches yoga at Friends for Life.

## Resources for HIV+ women, moms and moms-to-be

### ATLANTIC

**AIDS Coalition of Nova Scotia**  
Halifax, NS  
phone: 902.429.7922  
toll-free: 1.800.566.2437  
[www.acns.ns.ca](http://www.acns.ns.ca)

**AIDS Committee of Newfoundland and Labrador** St. John's, NL  
phone: 709.579.8656  
toll-free: 1.800.563.1575  
[www.acnl.net](http://www.acnl.net)

**AIDS New Brunswick** Fredericton, NB  
phone: 506.459.7518  
toll-free: 1.800.561.4009  
[www.aidsnb.com](http://www.aidsnb.com)

**AIDS PEI** Charlottetown, PEI  
phone: 902.566.2437  
[www.aidspei.com](http://www.aidspei.com)

### BRITISH COLUMBIA

**Positive Women's Network (PWN)**  
Vancouver, BC  
phone: 604.692.3000  
toll-free: 1.866.692.3001  
[www.pwn.bc.ca](http://www.pwn.bc.ca)

### Oak Tree Clinic

**The Women & Family HIV Centre**  
Vancouver, BC  
phone: 604.875.2212  
[www.oaktreeclinic.bc.ca](http://www.oaktreeclinic.bc.ca)

### The Hummingbird Kids Society

Burnaby, BC  
phone: 604.515.6086  
[www.hummingbirdkids.com](http://www.hummingbirdkids.com)  
*Provides support and services to kids living with HIV/AIDS.*

**British Columbia Persons With AIDS Society (BCPWA)** Vancouver, BC  
phone: 604.893.2200  
toll-free: 1.800.9942437  
[www.bcpwa.org](http://www.bcpwa.org)

**Healing Our Spirit BC Aboriginal HIV/AIDS Society** Vancouver, BC  
phone: 604.879.8884  
toll-free: 1.800.336.9726  
[www.healingourspirit.org](http://www.healingourspirit.org)

### ONTARIO

**Voices of Positive Women**  
Toronto, ON  
phone: 416.324.8703  
toll-free: 1.800.263.0961  
[www.vopw.org](http://www.vopw.org)

**Africans in Partnership Against AIDS (APAA)** Toronto, ON  
phone: 416.924.5256  
[www.apaa.ca](http://www.apaa.ca)

**Women's Health in Women's Hands**  
Toronto, ON  
phone: 416.593.7655  
clinic: 416.593.1815  
Tty: 416.593.5835  
[www.whiwh.com](http://www.whiwh.com)

**The Teresa Group** Toronto, ON  
phone: 416.596.7703  
[www.teresagroup.org](http://www.teresagroup.org)

*Provides practical assistance and emotional support to kids and families living with or affected by HIV/AIDS. Several programs are for new moms.*

**The Miriam Group** Burlington, ON  
phone: 905.681.7157  
e-mail: [miriamgp@idirect.com](mailto:miriamgp@idirect.com)

*Provides support to families living with or affected by HIV/AIDS.*

**AIDS Committee of London**  
phone: 519.434.1601  
[www.aidslondon.com](http://www.aidslondon.com)

**AIDS Committee of Ottawa**  
phone: 613.238.5014  
[www.aco-cso.ca](http://www.aco-cso.ca)

**Oasis** Ottawa, ON  
phone: 613.569.3488

### PRAIRIES

**HIV Edmonton Society**  
phone: 780.488.5742  
[www.hivedmonton.com](http://www.hivedmonton.com)

**Nine Circles Community Health Centre** Winnipeg, MB  
phone: 204.940.6000  
toll-free: 1.888.305.8647  
<http://ninecircles.ca>

### QUEBEC

**Centre de Ressources et d'Interventions en Santé et Sexualité (CRISS)** Montreal (QC)  
phone: 514.855.8991  
toll-free: 1.866.240.0090  
[www.criiss.org](http://www.criiss.org)

**Centre for AIDS Services of Montreal (Women)** Montreal (QC)  
phone: 514.495.0990  
toll-free: 1.877.847.3636  
<http://netrover.com/~casm>

**L'Hôpital Ste-Justine** Montreal (QC)  
phone: 514.345.4680  
[www.hsj.qc.ca/CISE](http://www.hsj.qc.ca/CISE)

*Through its centre for mothers and children with AIDS, Ste-Justine offers a variety of services, including pediatric care, anonymous HIV testing, pregnancy monitoring and gynecological care.*

**Les enfants de Béthanie** Montreal (QC)  
phone: 514.384.8160  
e-mail: [ledb@cam.org](mailto:ledb@cam.org)

*Provides a range of services and activities, including a summer camp, to kids, teens and families affected by HIV/AIDS.*

**Comité des personnes atteintes du VIH du Québec (CPAVIH)** Montreal (QC)  
phone: 514.521.8720  
toll-free: 1.800.927.2844  
[www.cpavih.qc.ca](http://www.cpavih.qc.ca)

### NATIONAL

**Pauktuutit Inuit Women's Association** Ottawa, ON  
phone: 613.238.3977  
toll-free: 1.800.667.0749  
[www.pauktuutit.on.ca](http://www.pauktuutit.on.ca)

**Canadian Aboriginal AIDS Network (CAAN)** Ottawa, ON  
phone: 613.567.1817  
toll-free: 1.888.285.2226  
[www.caan.ca](http://www.caan.ca)

This list is not exhaustive. For a listing of 100 community-based AIDS organizations in Canada, go to the Canadian AIDS Society at [www.cdn aids.ca](http://www.cdn aids.ca) or phone toll-free 1.800.499.1986.

### HOTLINES & WEBSITES:

**Motherisk HIV Helpline**  
toll-free (national): 1.888.246.5840  
[www.motherisk.org](http://www.motherisk.org)

*Click on the "HIV & HIV treatment" section for confidential access to info for pregnant women. Among other gems, the website offers a list of centres in Canada that provide pediatric HIV care.*

**Let's Talk** [www.kidstalkaids.org](http://www.kidstalkaids.org)  
*A website serving the needs of kids and families living with or affected by HIV/AIDS. Chat rooms, games, links and more. A program of The Teresa Group.*

**National Pediatric and Family HIV Resource Center (USA)**  
[www.pedhiv aids.org](http://www.pedhiv aids.org)  
*A wealth of info, including fact sheets, a newsletter and FAQs about care and treatment.*

**Camp Oasis Canada**  
[www.campoasis.com](http://www.campoasis.com)  
*A national summer camp for kids living with or affected by HIV/AIDS.*

**Camp Moomba**  
phone: 604.684.1701  
toll-free: 1.888.442.KIDS (5437)  
[www.campmoomba.com](http://www.campmoomba.com)  
*Free camp programs for kids living with HIV/AIDS.*

**Women Alive** [www.women-alive.org](http://www.women-alive.org)  
**WORLD (Women Organized to Respond to Life-Threatening Diseases)**  
[www.womenhiv.org](http://www.womenhiv.org)

**UNIFEM (United Nations Development Fund for Women) Gender and HIV Web Portal**  
[www.genderandaids.org](http://www.genderandaids.org)

**Women's Outreach Network (WON)**  
[www.womenfightaids.com](http://www.womenfightaids.com)

**Feminist Women's Health Centre**  
[www.fwhc.org/hiv.htm](http://www.fwhc.org/hiv.htm)

**Positive Women**  
[www.positivewomen.org.au](http://www.positivewomen.org.au)

**Canadian Women's Health Network**  
[www.cwhn.ca/indexeng.html](http://www.cwhn.ca/indexeng.html)

**AIDS Community Research Initiative of America (ACRIA)**  
[www.criany.org/treatment/treatment\\_edu\\_women.html](http://www.criany.org/treatment/treatment_edu_women.html)

**Project Inform: WISE words**  
[www.projinf.org/pub/ww\\_index.html](http://www.projinf.org/pub/ww_index.html)

**The Body**  
[www.thebody.com/women/women.html](http://www.thebody.com/women/women.html)

**Positive Women's Network**  
[www.pwnetwork.org](http://www.pwnetwork.org)

**New Mexico AIDS InfoNet**  
[www.aidsinfonet.org](http://www.aidsinfonet.org)

**AIDSinfo (U.S. Department of Health and Human Services)**  
[www.niaid.nih.gov/factsheets/womenhiv.htm](http://www.niaid.nih.gov/factsheets/womenhiv.htm)

[www.aidsinfo.nih.gov/guidelines](http://www.aidsinfo.nih.gov/guidelines)  
[www.aidsinfo.nih.gov/guidelines/adult/cw\\_02-04-02.html](http://www.aidsinfo.nih.gov/guidelines/adult/cw_02-04-02.html)



(from l to r) Shirley Sapsford, Lara Honrado and Roberta Vezina show off PWN's "Women and HIV Education Toolkit."

# Beauty

I have found beauty in so many places,  
 Not just in money or pretty faces.  
 I've found beauty in darkness, when I was alone,  
 In back alleys or under a stone.  
 I've found it in smiles,  
 I've found it in tears,  
 Sometimes in minutes, sometimes in years.  
 I've found it in giving of myself,  
 Or dusty old memories I'd left on a shelf.  
 I've found it in things I couldn't replace,  
 Like caring and trust in somebody's face.  
 I've found it in people who don't even know it's there.  
 And puppies and kittens who sit on my chair.  
 I've found so much beauty mixed with the pain,  
 By this time tomorrow I will find some again.

—Elizabeth (Betty) Anderson

Betty Anderson was born November 2, 1949, in Johnstone, Scotland. Among her AIDS-related work, Betty was a board member of Voices of Positive Women and Casey House Hospice. She was also a member of the Ontario AIDS Network's PHA Caucus and worked at PASAN (Prisoners' HIV/AIDS Support Action Network). Betty passed away on September 25, 2002, at St. Michael's Hospital in Toronto. She is dearly missed.



**The Positive Side**  
**Canadian AIDS Treatment Information Exchange (CATIE)**  
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 Toronto, ON M5V 3B1 Canada



**Mission:** The Canadian AIDS Treatment Information Exchange (CATIE) is committed to improving the health and quality of life of all people living with HIV/AIDS (PHAs) in Canada. CATIE serves PHAs, and the people and organizations that support them, by providing accessible, accurate, unbiased and timely treatment information. CATIE works in partnership with a network of other information providers to ensure that people have access to the information they need, in the form they desire, to make informed health care choices.

**This publication is available in English and French, on-line at [www.catie.ca](http://www.catie.ca), or by calling 1.800.263.1638.**

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**Disclaimer:** Decisions about particular medical treatments should always be made in consultation with a qualified medical practitioner knowledgeable about HIV-related illness and the treatments in question.

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## HIV Positive?

Having trouble finding local resources?

Looking for treatment information?

**CATIE is here for you. Let's talk.**

**CATIE IS CANADA'S NATIONAL PROVIDER OF TREATMENT INFORMATION FOR PEOPLE LIVING WITH HIV/AIDS, THEIR CARE PROVIDERS AND COMMUNITY ORGANIZATIONS.**

**Communicate interactively: 1.800.263.1638**

Speak anonymously with one of our knowledgeable Treatment Information Service Representatives about treatment questions or local resources in your area of Canada.

**Visit the CATIE Web site: [www.catie.ca](http://www.catie.ca)**

Read or download treatment publications and current news or find links to other Internet sites with information about HIV/AIDS.

**E-mail treatment questions to: [questions@catie.ca](mailto:questions@catie.ca)**

Ask questions of our knowledgeable Treatment Information Service Representatives when it is convenient for you.

**Become a CATIE member:**

More and more people and organizations are joining CATIE. Benefits include receiving updates on treatment information by e-mail or regular mail. Visit [www.catie.ca](http://www.catie.ca) or phone 1.800.263.1638 to join.



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