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). She's also a member of ATAC, the AIDS Treatment Activists Coalition (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)*

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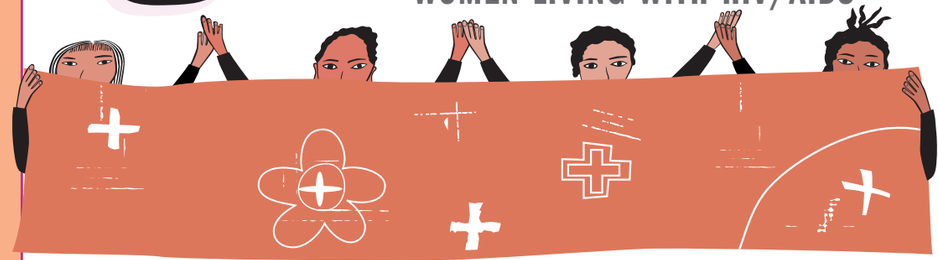
The Divine Secrets of the +Sisterhood

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

Illustrations by Beverly Deutsch

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

For more in-depth info, see CATIE's Fact Sheets on "Complications in Women" at www.catie.ca/facts.nsf

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 then 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 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.

Donna Garden, 38

Diagnosed with full-blown AIDS: 1991; CD4 count: 1,200; Viral load: undetectable. Vice-chair of the AIDS Coalition of Nova Scotia. Halifax, Nova Scotia

There's a need to pay more attention to the way the drugs interact in women. I'm on the birth control pill, and when I started taking Sustiva [efavirenz], the doctors couldn't tell me whether the Pill would work or not! Now they know it does work, but back then they didn't know. What do you mean, you don't know? You spent all this money on studies and you still don't know whether or not this medication interacts with something as important as pregnancy prevention?

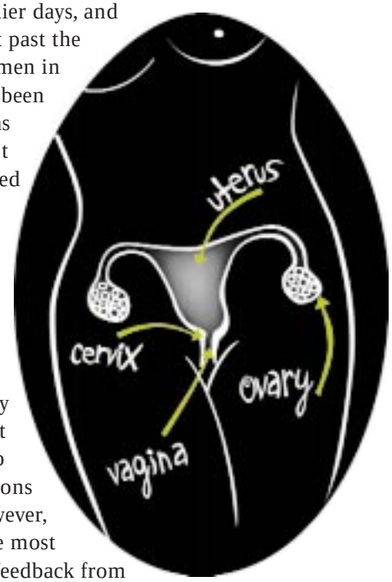
I find that my doctors listen more to me now because I know more. As I grew with the illness, they had to listen to me. They listen to me now because I won't shut up!

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).

For more in-depth info about HIV treatment, see CATIE's *Practical Guide to HAART*.

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_{10} 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*.)

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

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

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

Photo: Jake Peters

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, cerified aromatherapist

6. HORMONES

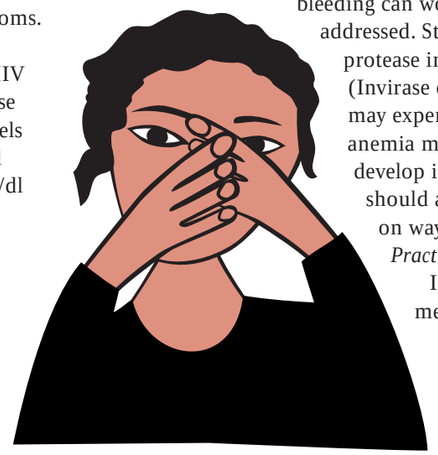
Research has shown that HIV infection can affect the body's ability to maintain normal levels of hormones — the chemical messengers produced by glands that affect countless aspects of body function. Four of the hormones most commonly affected are: testosterone, DHEA, estrogen and progesterone. These 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

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

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.

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_6 (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), 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.