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THE LIPO FILES

The Positive Side

The Positive Side

When photographer Jake Peters sent in some self-portraits to accompany his story about living with lipodystrophy (“Every Picture Tells a Story”), I knew I’d found our cover shot when I saw the one of him looking in the mirror. It’s a powerful image with many layers. In this private moment caught on film (by himself), Jake is gazing at his lipo-laden reflection and—this is why I find the image so compelling—beyond it. He’s on a journey through the looking glass.

We’d like to thank our readers—70% of whom are people living with HIV/AIDS—who recently accompanied us on our journey through the looking glass by responding to a survey about this magazine. When it comes to The Positive Side (PS), you are our mirror.

PS aims to shed light on what it’s like to live with HIV, so rather than providing the typical treatment info found in most HIV newsletters, our intention is two-fold: To bridge a gap in treatment information—between the medical and the personal; clinical and anecdotal; allopathic and holistic—and to connect the dots—between one’s physical, mental, emotional, spiritual and sexual health; between PHAs across the country; between one’s quantity and quality of life. In order to assess whether we’re accomplishing this, we need to look in the mirror from time to time—that is, to you.

So we sent out a survey with the magazine (Volume 6, Issue 1) and asked your opinion. Here are some highlights from the 266 reader responses we received:

Overall satisfaction: 91% of you are satisfied or very satisfied with PS.

8 reasons why asking yourself this question may make you healthier by Judy Weiser

BOOK REVIEW

Nutrients for Neuropathy

CHATTY CATIE

5 PHAs dish about disclosure

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RESOURCES

Emotional rescue

98% of you state that it’s valuable to hear the experiences of other PHAs when making decisions that impact your health.

Bridging the gap in treatment info: 98% of you state that it’s valuable to hear the experiences of other PHAs when making decisions that impact your health.

90% of you feel that you’re able to make decisions about managing your health.

Reaching out: 91% of you feel that PS helps you feel less isolated and/or more connected with the HIV/AIDS landscape in Canada. 94% of you recommend PS to colleagues and friends. 90% of you share info from the magazine with others.

Survey says: You’re happy to have a magazine about HIV with a Canadian focus. Chatty CATIE is a hit. You especially like the personal accounts of other PHAs—in your words, you find these stories “reassuring,” “helpful,” “empowering,” “valuable.” Many of you want to see more of these stories from your own neck of the woods.

You also gave us many suggestions about how to make the magazine even better. The bottom line is that you want more. More issues of PS, more stories, more voices, more diversity, more topics. You want to read more about: Aging, alternative therapies, “articles about how life with HIV can really suck sometimes,” dating, death, depression, disclosure (see Chatty CATIE, page 8), discrimination, going back to work, holistic living, how-to stories, interviews, long-term survivors, new treatments, parenting, pregnancy, rural info and issues, self-help, sex, side effects, spirituality, stigma, Tai Chi...more experiences and opinions from different ethnocultural communities.

One reader’s comment still stands out in my mind: After reading PS, I have a more global view of my situation as a human being: I can’t be defined by a virus!!! I have the impression that [I], the human being, who also has a fatal illness, have learned a few more tricks to help me face this disease...and life in general. As the editor, there’s no greater feedback I could imagine.

Thanks for letting us see ourselves in your mirror. We welcome your feedback, so please drop us a line (info@catie.ca) or call us collect at 1.800.263.1638 (ext. 291) if you want to contribute your stories or ideas to the magazine. In the meantime, enjoy this issue and take good care.

RonniLyn

Ronni Lyn Pustil
AIDS AIDS AIDS
I’m saying it
The world looks and sees what it wants
They have memorials written
They have you wasted and dead skeleton in your bed

AIDS AIDS AIDS
Oliver Wendell Holmes once said
“To find true happiness, get a terminal illness
and take real good care of your self”
real good care... pajama parties cookies & milk afternoon naps kinda care
lots of LOVE LOVE LOVE

I see angels flying above everyone’s head
I see miracles all day long
in oranges brown fat crawly bugs
on the big time journey across the towpath
ducks in winter Ginkgo trees raining yellow
GINKGO GINKGO GINKGO
my dog smiling and wagging its tail
to the rhythm of three sweet altos
“knock, knock, knocking on heaven’s door”

Rivers are always miracles
they aren’t stopped by rocks bridges boulders beer bottles
old tires dead bodies or even dead refrigerators
they go around over above under embracing all they touch
they never go back to the beginning to get it right
changing forever seeking accepting expanding being
We have mortal worlds filled with gods
Buddha Christ Vishnu Mohammed and Henry... the hitchhiker’s god
they walk us through to the end
shedding our named coats
our finely pressed out laid out figured out fitted in life suits
no expectations no more mundane earthly matters
9-5 skull famine weight loss facelifts fashion statements
free to go home the early release program
do the mambo till dawn safe sex erotic safe sex
free of judgment guilt and shame
death is for the dead and living is for every one else

AIDS AIDS AIDS
Hey I said it
don’t memorialize metaphorize hypnotize categorize or sanitize me
its hard enough living with an illusion no more definitions of my death
no more sympathetic death sentence eyes
I’m not dead dying no siree Bob I’m living
just thought I’d let you know

— River Huston

River Huston, 42, is an award-winning poet, author and journalist who was diagnosed with HIV 13 years ago. To read about her whole story, go to www.riverhuston.com.
Larry’s Story  For over a year I’d been counselling Larry about his problems relating to being HIV positive, trying to get him to realize that if he didn’t start to deal with all his worries and fears, and his deep secrets and stuffed-down feelings, he wasn’t ever going to regain his physical health (medically), no matter how many pills he took.

Then one day, he announced, “Guess what I just realized? Every time I have a thought, there’s a feeling attached!” It was a casual statement, yet it marked a major turning point for Larry’s health because it indicated that he was beginning to understand that his mind and body are deeply interconnected. He had started to realize that his physical (medical) condition was always going to be affected by his emotions and thoughts—no matter how much he tried to avoid them. Once Larry knew he couldn’t become physically healthier without first resolving all the other issues that were bothering him, he became much more willing to explore these problems in our counselling sessions. A few months later, Larry was not only healthier and happier but he no longer needed me as his counsellor because he’d learned how to take care of himself without my help.

Emotional Healing  Over the years I’ve learned from my clients and friends with HIV/AIDS that how people feel about having HIV influences not only their attitudes but also how they take care of their bodies (or decide if they want to). Usually people with HIV/AIDS (PHAs) are directed to pay attention mainly to the medical aspects of their treatment, as if maintaining their body’s health is their sole responsibility. Rarely are they given as much preparation for encountering, understanding or coping with all the inner feelings, complex thoughts and spiritual concerns that arise from an HIV positive diagnosis. Yet frequently the biggest problem for PHAs is not so much the specific medical aspects of HIV, but rather what HIV means inside their heart, mind and spirit. These things deeply affect the quality and direction of each person’s journey with HIV.

Having counselled PHAs for over a decade, I’ve seen proof that when people take better care of themselves emotionally, mentally and spiritually, they find that their lives become better balanced overall. Their body’s physical health usually improves as a result (because it’s directly connected to these other parts of themselves). This balance is important to overall health, in that a person cannot be truly physically healthy while emotionally distressed, spiritually troubled or mentally upset.

People can become physically healthier by learning how to resolve any “unfinished” emotional, interpersonal, family or spiritual difficulties. Sometimes they can do this on their own or by talking with friends or peer counsellors, while other times they might need the help of a professional therapist. Regardless of who helps you, one thing is clear: The more you can resolve your worries, fears and other troubles—and permit yourself to actually feel your feelings (and deal constructively with the consequences of doing this)—the more energy will automatically become freed up for improving your physical health. Each and every “bottled-up” feeling you have requires some energy to keep it in its “hiding place.” Once that energy is released as you work through your issues, you usually feel lighter and less depressed. You’ll also have more energy available for staying healthier—and, most importantly, wanting to.

Dealing with all the other-than-medical aspects of life with HIV will help you cope better and stay healthier longer—even though there’s no cure for HIV, you can find some healing in the meantime. As a result, you can begin to take back your own life to live (and love!) as fully as possible. It’s all a matter of balance.

Take more personal responsibility regarding your own medical care.  By becoming better informed about HIV, treatment options and the details of your own particular medical situation, you can become your doctor’s partner in deciding what’s best for you. It’s your responsibility to keep your body as healthy as possible, not your doctor’s.

There are many things you can do for your body to improve its medical condition, such as reducing stress (relax through yoga or meditation, exercise, enjoy activities not related to HIV). Your body could also probably use some attention to what’s being put into it (or not!), so perhaps it might be useful to consult a nutritionist or dietician to see if there’s any room for improvement.

Don’t deliver yourself to your doctor like a blank slate—arrive at appointments with knowledge, questions and the attitude that you deserve to have your questions answered. After all, it’s your body that you and your doctor are working together to heal.

Explore (and clear) emotionally complex issues that are living deep inside you.  I think of all the things you’d like to change but can’t, all the things you’d like to tell somebody but are afraid to, all the secrets you’re worried somebody will discover, all the addictions you’re going to deal with “someday,” all the “what if’s” and “I shouldn’t have’s”—the things that keep you from sleeping well or having fun. These issues are complex, and it takes a lot of energy to ignore them or keep them buried. Few people can figure them out by themselves. That’s why there are counsellors to help you review your life and clarify what you want to change or improve. In the process, you’ll likely encounter moments when you feel overwhelmed, depressed or powerless, but by talking about these things you can recognize their effects on you and learn how to cope better with such feelings.

Think of everything that’s troubling you right now, and imagine for a moment that these issues have been resolved. Ahh, that would be a big sigh of relief, wouldn’t it? So, what’s stopping you from getting started on this journey? Your troubles are already inside you, bothering you whether or not you face them. By beginning to confront them (in a safe environment where someone can help you explore and resolve them), at least you have a good chance of removing their power over you. Your heart will feel a lot lighter as a result.

Encounter (and experience) negative feelings rather than avoiding, denying or numbing them chemically.  It’s only natural that when we’re hurt we try to protect ourselves. We sometimes try to lessen the pain in a number of ways (by getting revenge, ignoring it, numbing it with recreational or street drugs, or giving up and being depressed so we don’t feel anything anymore), but none of these things actually takes the pain away. It usually just buries itself deeper under many layers of protection, sometimes to the point where we don’t even realize it’s still there.

In order to heal these hurts, they have to be encountered or we won’t be able to get rid of them. When things are deeply buried, they have a bad habit of popping up when least expected. When that happens, you can suddenly arise all at once, and this can be frightening.

Living in fear of experiencing your feelings means they still actively run your life (even when you’re trying to avoid them), because if our feelings define how you live. If “bumpy” feelings don’t get resolved, they’ll come back to haunt you—either directly, by erupting, or indirectly, by making you depressed or physically sick (or worse).

Feelings and thoughts are alive (like the air that surrounds and sustains us) even if they can’t be seen. Feelings are busy “doing their thing” inside us, whether or not we’re aware of them. So when times get bumpy and
Perhaps this uncertainty means it’s time to get on with your problems. Helps ease their negative effects on how you react to them. When you cope better, your whole healing has begun. Although you may not be able to do much about the circumstances of your life, you can begin to experience your feelings rather than avoid them, so that small crises don’t get bigger than they need to. If you think of yourself as tainted or cursed by HIV, that’s somewhere less of a person because of it, then the virus wins—and thus you’re “dead” anyway, even though your body is still alive. You must be able to separate your own life from that of the virus, so that reducing it inside you doesn’t also reduce your self in the process. Here’s the formula: “You minus HIV equals what?”

**Develop a support network where it’s safe to ask for, and receive, emotional support.**

It’s important to let others give you emotional support. Having a support network that you’re willing to nurture and maintain becomes a reciprocal arrangement you can count on. You will need help occasionally—we all do. The trick is to find this without having to give up your self-respect in the process. Knowing you’re willing to offer emotional support in return makes it easier to accept it from others. When you let others begin to care about you, you usually find yourself starting to care more about yourself.

**Became more of an activist (at least personally, if not politically).**

There’s an old Quaker term called “bearing witness.” It means that if you see or know of something wrong happening, even if you can’t stop it, at least you can make sure it’s known that you’ve witnessed it so it doesn’t pass unnoticed with invisible consequences. Bearing witness can be very empowering because it helps people escape from being powerless victims. HIV/AIDS is political, and activism at any level can be helpful—even just refusing to view HIV as a death sentence is a personal-political action. Activism isn’t just a powerful political tool at community levels, it’s also individually empowering and health-enhancing in its ability to effect change inside the person who makes a stand—even through simple, quiet actions like volunteer work or writing a letter of support. Anything you put your hand in hand with education and accessibility and assisting those with less power—and the result is that you yourself grow in the process.

**Find a way to have more “AIDS-free downtime.”**

Everybody needs time in their life “to breathe,” time when HIV isn’t in your face 24/7, when who you are inside yourself is more important than your relationship with the virus. Even though it never goes away, HIV can be put aside for a while so you can have a rest from it. It may well be part of your life but it doesn’t define your life as a whole and therefore should not be allowed to control it (see #5).

Instead of HIV always riding around on your shoulder no matter where you go, try to relabelling your life better by finding a way to move HIV to a parking space nearby—where you can reclaim it when you need to, but where it can otherwise sit there gathering dust and not drive you to crazy places. Usually when you’re having fun, the HIV somehow isn’t “there” so much. This sort of “AIDS-away time” helps people move HIV a little further away from their mind (and heart), much like the way that being on holiday works problems fade into the background.

Of course, this list can’t be done all at once, but each point is a step forward, no matter how slowly it is begun. If you can simply begin to find more reasons to want to live another day or week—something that gives your life a bit more meaning and purpose, that makes your feelings more worth exploring and encountering—then you’ve begun the path of healing inside your heart and spirit. When you have a reason to live, and begin to more fully live the emotional parts of your life, you’ll be in better balance overall. Your physical health will have a better chance at improving and hopefully will carry you long enough until the cure is found (or until you die of old age).

People can move from being passive victims to being active participants in their own lives, thereby gaining more control over what’s being done to their body. People can begin to realize that what they put into their mind and heart is at least as important as the medications and nutrients they put into their mouth. All of us are eventually going to die, nobody gets out of here alive. But we can try to live as fully as possible in the meantime—because the more we live, the less we die while we’re still alive. HIV can be made to take a backseat rather than running your life. As the poet James Baldwin wrote: “If you don’t live the only life you have, you won’t live some other life; you won’t live life at all!”

**Strengthen your personal coping skills so that small crises don’t get bigger than they need to.**

Although you may not be able to do much about the circumstances of your life, you can do something about how you react to them. When you cope better, your whole attitude improves and your mental and physical condition takes on less of a crisis atmosphere. Learning how to cope better with your problems helps ease their negative effects on you and leaves room to enjoy the simple pleasures of daily life. Living in the moment becomes richer once you realize that “now” is really all that anyone truly has.

Yes, HIV may kill you, but then again, it may not. Perhaps this uncertainty means it’s time to get on with your life rather than being hesitant about it, because it may not end like you expect. Wouldn’t you hate to get all the way to your senior years never having lived in the first place because you weren’t able to see beyond your diagnosis?

Separate your illness from yourself (and your self from its stigma).

You may have HIV, but it doesn’t have to “have” you. HIV is not who you are; you are much more than HIV. It’s a virus, a medical condition—nothing less, nothing more. Self-violent, self-intellectualized homophobia do not have to automatically accompany having HIV.

Meds, Senneff, a PN’er himself, knows the terrain. (Be sure to tell your doctor about your supplements plan to take.) The reader-friendly descriptions of antioxidants, minerals and herbs, and how they strengthen nerve function, soothe just about everyone.
Duane Morrisseau, 34

I had to disclose to two families because I’m adopted. As soon as I was diagnosed, I told my non-Aboriginal adopted family. They responded with “you’re a liar.” That was pretty much the final straw of the strained and abusive relationship I had with them. As a young, Two-Spirited man, I needed support, but I had to carry the burden of having HIV by myself. As a woman I lived in complete fear for three years. I started drinking heavily, feeling angry and self-hating, and inflicting harm on myself. I started drinking at 15 to numb things because of my upbringing. This was pretty much the scenario of what it was like to have an HIV-positive diagnosis. It becomes evident that the health issues you’re talking about are a lot broader than HIV. I started to check out my background and searched out my Aboriginal family. I told my mother the first time I met her: “I’m Two-Spirited and I have HIV.” I had nothing to lose. She said: “You are my son, you love your community.”

Though disclosing has been positive for me, I don’t go second disclosing to everybody. I do it when I’m asked to do the work, and I do it with my heart. There are many levels of disclosure—your personal life, family life and professional life. I disclosed to my family in a much different way than I disclosed to groups. The key is to find support within your community.

Advice: Hold your HIV status close to you. It’s yours until you feel that someone in your life deserves to hear your story. Although there are laws that are supposed to protect PHAs, in my opinion, they don’t. When I meet anyone now, I want to get to know them before disclosing and discuss discrimination and stigma.

Becky Beveridge, 26
Unemployed, Diagnosed with HIV, 1990.

Viral load: unknown. CD4 count: 100.

When I disclosed my HIV status, I couldn’t believe it. In the next seven years, I had four more tests…and I still couldn’t believe it was in blood, so afraid of HIV, I couldn’t admit to living with it.

My friends and family didn’t know I had HIV until 1998. I didn’t tell them because of the stigma and discrimination. Also, there was basically no treatment available for PHAs in Kenya, so I was afraid to say, “Hey, I’ve got HIV and I’m going to die.” Then, I was going to die soon because I had no access to the medication.

When I came to Canada I heard about the new medications. I knew I had to live. I had to stay here. It would have been foolish for me to go home to Kenya. She was 7. She was never tested for HIV. After she died, I was finally able to accept that I had HIV, it was much easier for me to deal with all the issues around the virus.

When I learned of my HIV status, I was in denial, so afraid of the discrimination and abuse. I was in a nightclub once. I’ve never been in a bar. I’ve never been a drug addict until then. I felt like I was marked by the disease, that each time people looked at me they thought of the movie Philadelphia. I started isolating myself, crying a lot, and taking drugs and alcohol. I’m HIV positive. I’m drug-free. I’ve ended drinking because of the health issues you’re talking about are a lot broader than HIV. I started to check out my background and searched out my Aboriginal family. I told my mother the first time I met her: “I’m Two-Spirited and I have HIV.” I had nothing to lose. She said: “You are my son, you love your community.”

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I first noticed lipodystrophy in my face after I came out of the hospital in 1996, 12 years after I seroconverted. I began to fear it when I understood that my sunken face, exposed ribs, swollen belly and bony arms and legs marked me as a Person With AIDS.

I spent more than a year in that hospital. When I left, I was in a wheelchair and I looked like I was starving. At 66 kilograms I was emaciated, fragile and unable to walk. My muscles had atrophied.

My occupational therapist suggested that I attend a program called “Positive Living” at the YMCA to try to build up my strength. I had a difficult time

Looking at myself in the studio’s full-length mirror. My ego was shattered. I had a gigantic gut, spindly legs and arms and a huge hump on my back. (OK, it wasn’t huge, but I had a hump and it was growing.) My hair was falling out. I looked horrible.

I had a hard time accepting my appearance, seeing myself as a person whose illness was so visible on my face and body. I never wanted to take my clothes off.

In one of my Stretch and Strength classes at the Y, a woman came up to me and said, “Take it easy! Your veins are bulging! You’re overexerting yourself.”

We hadn’t started the class. Veins were bulging out of my skinny limbs, like ropes wrapped around my arms, legs and feet. They still do. It’s my normal appearance.

I believe that lipodystrophy has had a major impact on how people respond to me. I think that people who recognize the syndrome in my face choose to not associate with me, whereas if my face were chubbier, it would be easier to make friends.

I used to feel uncomfortable eating because my gut would distend even further. My waistline would expand from the pressure. Everything was forced outwards. Tying my shoes was exhausting because I could hardly bend over. I found it difficult to breathe. I felt like a big pimple that needed squeezing. Having too much fat in some places and not enough in others was a bit like geopolitics—this great big ballooning gut and hollowed out cheeks (at both ends), sunken eyes, spindly arms and legs.

I have closets full of garments of ghastly girth. I have closets full of friends.

I have closets full of friends. It’s time to part with the old clothes because I’m longer fit me when my belly swelled 14 inches and I lost my ass. I’m glad I hung on to my old clothes because I managed to get my figure back. It’s time to part with the garments of ghastly girth.

I love to push my limits and when I’m doing yoga I forget all the things that trouble me—I’m only aware of myself at that moment. When I practice, there’s a dialogue between my body and my brain. I find incredible satisfaction in bodybuilding through mental control.

Diet and exercise control my diabetes. I feel incredible satisfaction in bodybuilding through mental control. I find incredible satisfaction in bodybuilding through mental control.

Once I found the inspiration—after training at the Y, feeling a bit better about my body and developing a sense of hope—I began to search for something more than sit-ups and exercises I wasn’t finding any joy in. Aerobics was wearying, and I began to find basic Stretch and Strength classes rather predictable and unchallenging. I also had little love for weight training with those big machines. It all seemed like work. I yearned for something I could do at home or on the road, that didn’t require a membership card or special equipment.

Yoga gave me that. It simply required that I find a teacher to inspire me. And I did—my teacher has been guiding me for five years. I knew from the first class that doors were opening for me.

Yoga has helped me in many ways. It’s taught me to become self-disciplined and learn to feel my body from within. With yoga I’ve managed to massage and coax away some of the obvious symptoms of lipodystrophy.

I’ve gradually adapted my lifestyle to accommodate living with the virus and the side effects that go hand in hand with my meds. I quit smoking in 1988 when I saw a friend struggling with PCP in an intensive care unit. I cut out drinking. I drive a bicycle. I’ve changed my diet at the urging of my yoga teacher and dietitians. Avoiding red meats, animal and trans fats, sugar, salt and junk food has lowered my cholesterol and reduced hypertension. I eat high fibre foods: whole grains, nuts, fruits, vegetables, some fish, and only dairy products that are 1% fat or less. I eat high fibre foods: whole grains, nuts, fruits, vegetables, some fish, and only dairy products that are 1% fat or less.

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Had I not started HAART when I did in the course of my treatment, I've received unquestionable benefit from antiretroviral therapy. Changes wouldn't be a good idea. Diagnosed with HIV in 1989, I was treated for lipodystrophy with medications. I have elevated cholesterol and triglycerides, which is being managed with medications.

Lipo may include such physical symptoms as:
- Fat accumulation—increased fat around the stomach and waist; enlarged breasts (especially in women); build-up of fat at the base of the neck ("buffalo hump");
- Fat wasting—loss of fat in the arms and legs, hips, butt or face;
- Lipodystrophy may include the following laboratory test results:
- Elevated lipids (fat)—increased levels of triglycerides and cholesterol in the blood; which can lead to increased risk of heart disease;
- Insulin resistance—a condition in which the body becomes less sensitive to the hormone insulin (which is used by the body to help maintain blood sugar levels); this results in higher-than-normal levels of blood sugar and, over time, increases the risk of diabetes.

Some people may have one symptom and others may have several. Because nobody understands exactly what causes lipo and why it happens, doctors don't know how to prevent it or reverse it. Because lipo was first noticed in the mid-1990s, after protease inhibitors (PIs) came into widespread use, much of the blame for lipodystrophy is put on these particular drugs. However, PIs are not the only drugs that have been implicated in lipodystrophy. Other lipo risk factors include:
- Genetic predisposition
- Increased body mass index (fat-to-muscle ratio)

The changes in my appearance have most definitely had an impact on my self-esteem. Let's just say I no longer get as many phone numbers. This has been a grievous loss for me; it certainly is one of the more challenging things I've had to deal with. However, it's taught me to appreciate and accept other qualities in life. I'm grateful for the diversity of intimate and sexual experiences I've enjoyed and I don't consider myself by any means "underprivileged" in this area. Some guys still find me attractive and I take advantage of opportunities when they arise!

One of the lessons I've been forced to learn about myself is that I'm more than just a pretty—or not-so-pretty—face. I'm a whole human being with an abundance of good things to contribute to this world. I keep this thought topmost in my mind as I carry out my daily activities. I've discovered that humans are very adaptable in the face of adversity. I'm amazed at the journey I've taken in learning to live with lipo.

Our personal appearance influences to some degree many aspects of our lives—everything from employment prospects to dating and other social opportunities. As a gay man, I'm aware of a subculture that seems, on the surface at least, to place a great deal of importance on physical appearance. Just pick up any gay newspaper or magazine and look at the ads.

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One of the lessons I've been forced to learn about myself is that I'm more than just a pretty—or not-so-pretty—face. I'm a whole human being with an abundance of good things to contribute to this world. I keep this thought topmost in my mind as I carry out my daily activities. I've discovered that humans are very adaptable in the face of adversity. I think this experience has made me a generally more compassionate person. I hate to use a cliche, but when life hands you a lemon, make lemonade.

I lost my younger brother to AIDS in 1994, before HAART became available. I know that in his last months of life his appearance was the least of his worries. I don't understand why I was spared the calamity that he suffered. But it does make me even more appreciative of my survival and the quality of life I enjoy.

Wayne Stump has been a volunteer at CATIE for seven years and won the Volunteer of the Year Award in 2002. If you'd like to share any thoughts on this subject, please e-mail him at wayne@catie.ca.

For more info on lipo, see CATIE's Practical Guide to HIV Drug Side Effects at www.catie.ca/sideeffects_e.nsf.
I MADE SOMEBODY CRY ON THE FIRST DAY OF OUR WRITING GROUP.

Ten of us were gathered at the big wooden table in our meeting room. We’d all written our first stories and were supposed to volunteer to read them out loud. Like swimmers at camp by a strange new lake, we all wanted to swim, we were there to swim, but nobody wanted to jump in first. What would everyone think when they saw me in my swimsuit, all bony ribs and weird birthmarks? Maybe someone else will go first...

Mark did. He calmly, slowly read a story about calmly, slowly smoking a cigarette—in the smoking room of the psych ward where he’d stayed for a while after being diagnosed with HIV. I could practically taste the curls of smoke, see the cracked orange plastic chairs.

We were all quiet for a minute after he finished. Then I broke the silence, telling him his story was very, very good. That it was understated, moving, and that I could relate to losing it a bit myself after my own diagnosis. That’s when I noticed him crying, with relief. So I said, “It’s no fun till somebody cries,” and we all cracked up and started owning up to how vulnerable we felt. Just like any support group, but more so: We weren’t just sharing our feelings and thoughts, we were writing them down. Even scarier! Not just worrying about how weird or pitiable we might sound, but about writing badly.

One of the first lessons we learned was that in our group there was no such thing as writing badly—the only crime was writing dishonestly. We weren’t there to be Melvilles and Alice Walkers; we were there to write—for each other, but mostly for ourselves. No worries about grammar, spelling or metaphors. Not having to say the sky was “cerulean” if you could simply say “blue.” Just writing about what was important to each of us, as honestly as we could.

Dr. Allan Peterkin, staff psychiatrist at Mount Sinai Hospital in Toronto, started the narrative group along with occupational therapist Julie Hann as a therapeutic activity for people with HIV/AIDS. The idea was that writing about our experiences could help with the stress and trauma of living with this disease. We met every Monday for 12 weeks, each session gently and capably led by Allan and Julie. Every week there was a different assignment. The topics were big and spacious: Write about an experience with the health care system. Write about a decision.
You could write your piece as long or short as you liked, on topic or not, at home during the week or in the meeting room just before the session. Each week, two or three people would read aloud what they’d written. Then the rest of us would give feedback—what was strong about the story, what might have been done a little differently, which directions we thought it might have gone in. We quickly discovered that at least two people are involved in each piece—the writer and the reader—and that the reader often hears things the writer wasn’t even aware of.

I tried to write honestly and not worry about how “good” it was. I wrote about some of the strange and difficult things that have happened to me: Relationships on the rocks. Having a camera stuck up my butt to look for cancer (thankfully, not finding any). The mixed emotions I felt when people I didn’t care for very much died. (thankfully, not finding any). The mixed emotions I felt

I thought the majority of my stuff sucked. Most of my stories came out awkward and raw—all bony ribs and weird birthmarks. In my work providing AIDS treatment information, I’m used to writing about medications and viral loads, not personal, human experiences. Writing I could handle, but this somehow felt like loads, not personal, human experiences. Writing I could

There was one thing that haunted me, one thing that hovered quietly and invisibly nearby, biding its time. Near the end of the 12 weeks, when Julie turned the page on the flipchart and I saw the words write about a goodbye, I knew the time had come.

I didn’t know if I could do it, if I should do it. How dare I presume to take my friend’s death, his life, and capture it in a page or two of my clunky words? How could it possibly be worthy of him? How dare I steal it from him like that?

And yet I did. I wrote about standing at Simon’s bedside as he died, that final moment frozen forever in time. I wrote it crying, then sobbing, sometimes barely able to see the words. I edited and polished it, trying to do it justice. And I read it aloud to the group. (See “The Blackbirds,” next page.)

Everyone was silent for a while, as we usually were after a particularly personal or painful story. Then, one by one, people told me what a person Simon must have been to inspire such feelings in me. And what a friend I must have been to care so much about him. Then it was my turn to cry a little more.

The group wasn’t always so intense, thank goodness. Bob, who could write like blazes, penned what Allan called a “postmodern striptease” about webcam sex (adjusting the camera angle to hide his lipodystrophy). Earl wrote about his ex-girlfriend, Wayne about his ex-boyfriend, and Gail wrote about her childhood town. We wrote about gay bashings, homeless old men on park benches, coming out as positive.

Some of it was very good. Some of it, honestly, was not. It never mattered. We didn’t need to be told not to trash somebody else’s story because it didn’t sound like Shakespeare. There was always something that made us say, “Wow, thanks for sharing that.”

The only real literary “rule” was to try to show, not tell. That could be a challenge. It’s easy to tell you that my ex-boyfriend was cold and uncommunicative and that I resented him for it. But it’s way more interesting to describe an incident where I tried to connect with him and how he turned his back, and let you draw your own conclusions.

Shortly after the group ended, I saw Bob’s webcam-sex piece in a local magazine. A published writer! For me, the changes have been subtle but profound. These days I feel a bit twitchy if I don’t have a notebook handy. That nagging, censoring voice that says “nobody needs to hear this” hasn’t quite shut up (and probably never will), but it’s gotten a lot quieter. I think my writing has improved, and I certainly spend more time doing it. But the point of the group wasn’t to turn us into burgeoning novelists—it was to help us make sense of our experiences, to find some meaning in the often-painful events we live through.

Now I can tell you about my cancer scares, about standing by Simon’s bedside during his last moments, about the narrative group itself and how I learned to write about these things. And it feels as though it matters. That by telling it I’ve made something a little meaningful, a little lasting. That whether it’s first-rate writing or clumsy chicken-scratching, happy or sad, funny or serious, someone may read it and be affected, may find something that stops them for a moment and makes them think “ah.” That I’m a slightly bigger part of the big, wild web of human life. And that, to me, seems worth the effort.

I’m signing up again in September.

Derek Thaczuk tested positive 12 years ago and has worked at the Toronto PWA Foundation for seven years. His other writing credentials include the Canadian HIV/AIDS Law Review and the AIDS Committee of Toronto’s erotic story writing contest. He lives in Toronto with his cat, his books and his sweetheart of nine years who lets him write on the walls.
I see the birds between the rocks
the crows that knew your name
and came on time.
I saw your eyes
we held your hands
what did you think about
until the angels came
lights out

―Diamanda Galás, “Birds of Death”

THE BLACKBIRDS
I NEVER TOLD SIMON ABOUT THE BIRDS. Even when they began to gather in the darkened corners of the hospital room, and we all knew the time was finally near.

I wondered where he was: What inner landscape he was travelling, tethered so thinly to his frail body? Was it comforting? Frightening? Was he aware of one at all?

We could never know. He’d been unconscious for days. A mercy. The ventilator prevented speech. How it had frightened him when it began breathing for him. We’d soothed him with touches and words until the convulsions stopped.

His mother asked, surely I’d been through this before? I said no. Not like this. Not with a friend.

Days ago. How many? Time had lost its meaning.

It did not surprise me when the birds arrived.

I wanted to kneel beside the bed, put my hand on Simon’s forehead and my lips to his ear, and tell him not to fear the black birds now gathering at his side. Don’t be afraid of the sternness of their look, of their carbon-black, diamond-brilliant eyes, of the chill wind as their wings come flapping blackly down.

They are your friends. Your ferrymen. They are here to see you safely through. To see that no harm comes to you, now on this final journey. You, who’ve already travelled through so many horrors. Their sharp eyes, their sharp claws are here to keep you safe, my friend. Don’t fear.

All this I told him silently.

And when the final bird arrived and said, it’s time, and the jagged lines on the machines began to plummet and his mother softly said, “My God,” and we all drew closer to his side, all I said to him was, goodbye Simon. The chorus of our voices: We’re all here with you. We love you. Goodbye, lover, son, friend. Lights out now.

Don’t be afraid.

Goodbye. ❇

―Derek Thaczuk

We buried Simon’s ashes under a sapling cherry tree in front of Trinity College at the University of Toronto, where he’d spent his happiest years. The last few days while working on this story, I visited his tree—in full July glory in the midst of the beautiful grounds of the bustling campus—and thought about all the atoms that used to be Simon, now growing into this gorgeous tree in his favourite place.

THE WRITE STUFF
Wanting to explore what he calls “the interface between writing and therapy,” Dr. Allan Peterkin, staff psychiatrist at Mount Sinai Hospital, attended some writing workshops at the University of Toronto along with occupational therapist Julie Hann. They then enlisted U of T’s director of professional writing, Professor Guy Allan, to help adapt his workshops for use by PHAs.

Treating writing as therapy, they borrowed some tactics from art therapy groups: The focus is on the work itself. “Pseudotopics” give writers the necessary freedom. Groups are small (less than a dozen people), and confidentiality keeps the process safe.

Five groups have run so far—two a year since the first session in January 2001. Most participants have reported that the sessions helped them deal better with their illness.

By “nudging personal stories into narratives,” as Peterkin puts it, experiences become more understandable—to other people and, perhaps more importantly, to the writers themselves. Stories take on a permanence and meaning when they’re written down on paper—as one participant put it, getting them “out of my head and out into the world.”

Got writer’s block? Peterkin and Hann offer up the following tips:

1. Write for yourself. Don’t even think about who might read it later.

2. Pace yourself. Go at your own speed. Something is always better than nothing.

3. Muzzle your inner critic. Forget the rules. Take risks! Writing is an exploration, so go on, explore.

—Fall/Winter 2003
THE OTHER WORD
HERPES: THE HIDDEN EPIDEMIC
by Katherine Ota

AS ILLUSTRATED IN THE ABOVE LETTER TO POZ MAGAZINE’S “SEXPERT” IN THE APRIL 2003 ISSUE, ALTHOUGH BEING OUT ABOUT HIV IS MORE AND MORE COMMON THESE DAYS, BEING OUT ABOUT—OR EVEN TALKING ABOUT—HERPES IS AN ENTIRELY DIFFERENT MATTER.

I got genital herpes in 1982 from my new boyfriend at the time, Oded, who had no visible signs of it the first time we had sex, nor did he during the two years I was involved with him. I hadn’t had sex with anyone for a year before we got together, so there was no question as to whether I was infected by someone else.

Amazingly, looking back on it now, but perhaps not unusual for a young woman in love, I never told Oded when I had my initial outbreak just a few days after we first had sex, and I never once brought up the subject during our two years together.

For the next few years, I had one or two outbreaks a year. They only lasted for a few days, tended to occur in the same place in my vulva and were not really that much of a bother. Following in Oded’s footsteps, I never told any of my subsequent lovers about my infection, as I didn’t have outbreaks very often and when I did it was always when I had my period—an easy excuse to avoid intercourse.

Ten years later, after one bout of Bell’s Palsy, two bouts of shingles and one of pneumonia, the herpes outbreaks became much more frequent. I also discovered that I was HIV positive during this period. A few years after that, during my second bout of Pneumocystis carinii pneumonia (PCP), herpes lesions exploded all over my vulva and bum, and I unknowingly spread the infection to a finger that had a small cut on it. Up until that point, I had never taken an antiviral or antiretroviral medication. Having witnessed the death of so many people with HIV/AIDS who were treated by “experts” with these drugs in the late 1980s and early ’90s, I’d formed a strong distrust of both the medicines and the specialists.

However, after one month of having large lesions on my bum and finger, and having had the PCP successfully treated, I finally agreed to take acyclovir (Zovirax). When the lesion on my finger cleared up and those on my bum were reduced to about two, I lowered the dose of acyclovir (it made me feel awful) to the minimum that would keep the infection from spreading. After about six months of living with this condition and not being able to sit down (did I mention that I’m rather stubborn?), I realized that things were really not improving and were really not likely to. So I finally decided to see a well-known HIV specialist, deal with the herpes and start antiretrovirals.

The specialist put me on intravenous (IV) foscarnet (Foscavir) for one month, which made me feel progressively weaker—but the remaining lesions did clear up. She then told me that after starting the antiretrovirals I should overlap them with the IV foscarnet for one week and then stop the foscarnet altogether. When I asked her what I was supposed to do for a prophylaxis for the herpes after going off the foscarnet (by this point I had started to read medical literature), she said that I wouldn’t need any once I started the antiretrovirals and experienced an increase in my CD4 count. Unusual for me, I decided to follow the advice I was given.

That was a big mistake. Things went from bad to unbelievably horrible. Not only did I have terrible reactions to the drugs—nausea, vomiting, constant migraines, hallucinations, insomnia—but because everything was so intensely terrible I didn’t notice (or perhaps didn’t care, as I would have been happy to go on to the next life at that point) that I started to have a herpes outbreak. On top of all of this, I realized there was something wrong in one eye. By the time I’d been diagnosed with cytomegalovirus (CMV) and switched to a new, sympathetic doctor, herpes had exploded all over my vulva, bum, finger and the palm of my hand—much worse than it had ever been.

May I suggest that no matter what any doctor tells you never stop prophylaxis for herpes when you first start antiretrovirals.

Since that time, around 1998, thanks to a wonderful new HIV specialist, a naturopathic doctor, a stabilizing period on IV ganciclovir (Cytovene) for both the CMV and the herpes, and a simpler antiretroviral regimen which I’m able to tolerate, my overall health has improved considerably. My current CD4 count is 1,454, up from 57, and my viral load is undetectable, down from about one million.

However, my herpes problem persists. While my doctor recommended 800 mg of acyclovir three times a day as a suppression dosage because my infection is so extreme, I’ve experimented with lower doses. Less can sometimes be just as good, if not better, than more, and quite frankly, I’d rather take the least amount of drugs into my body as possible. For the past four years I’ve been able to keep the herpes suppressed with a daily dose of 1,000 mg (two and a half 400-mg tablets daily); once or twice a week, I lower this to 800 mg per day (two 400-mg tablets).

I’ve also learned through much trial and disappointment that I absolutely cannot eat chocolate or nuts without triggering a herpes outbreak (see Nutrition, page 20). When I start to feel one coming, which for me is small bumps on my bum, instead of increasing the dose of acyclovir, I simply take things a bit easier, get more rest and make sure I’m eating well. The bumps then subside in a few days without breaking the surface.

Herpes 101
Genital herpes is a very common and highly contagious sexually transmitted disease (STD), affecting at least one
out of four (about 50 million) Americans. As there are next to no statistics on genital herpes in Canada—even Health Canada quotes American statistics in its publications—it would seem reasonable to assume that the rate of infection here would be similar.

This treatable but incurable STD is most often caused by herpes simplex virus 2 (HSV-2), and sometimes by herpes simplex virus 1 (HSV-1). HSV-2 usually affects the genital area, and HSV-1 the mouth, lips and nose. However, through oral sex HSV-1 can be spread to the genitals and HSV-2 can be spread to the face. The stigma associated with genital herpes is not associated with oral herpes, which is usually referred to as cold sores or fever blisters. Genital herpes, however, is always referred to as herpes.

It is believed that more than 80% of people who have genital herpes are not aware that they have it, as they haven’t experienced any symptoms or haven’t recognized them. Transmission often occurs by people who aren’t aware that they’re infected or that they can transmit the infection when they’re not having an outbreak. It is also not uncommon for people who know that they’re infected to not disclose this information to their sex partners.

Initial infection
The first signs of genital HSV usually show up two to 10 days after exposure. Early symptoms could include:

- itching or burning sensations
- swollen and/or sore lymph nodes
- fatigue
- mild fever
- vaginal discharge
- headache
- muscle pain

A few days later, painful clusters of small fluid-filled blisters, bumps or sores (also called lesions) appear in the genital/anal area—on the penis, inside and around the vagina, on the thighs or buttocks. These blisters usually burst, become raw and painful open sores, then crust over and heal without scarring. Lesions can also develop in the urinary passage, making it painful to urinate.

Recurrents
After the initial outbreak, herpes most often lives dormant in nerve tissue in the spine—in the top of the spine at the base of the neck, and at the base of the spine, in the sacrum. When reactivated, it multiplies and travels along the nerve pathways to the surface of the skin. It can stay dormant for years before recurring. Some people only experience one outbreak in their whole life; others have a few a year. Women generally experience them more often than men and tend to have outbreaks around the time of their period, when their immunity is lower. And then there are those whose outbreaks are so severe that they always have to be on suppressive antiviral medications. Even while on antivirals, they sometimes still experience outbreaks.

Among HIV negative people, recurrent outbreaks are usually less severe than the initial outbreak and often become even milder over time; this is not always the case for HIV positive folks.

Transmission
HSV can be transmitted sexually through:

- kissing
- vaginal and anal intercourse
- oral sex
- skin-to-skin contact

Parts of the body highly susceptible to infection are the cervix, urethra and any areas that are subject to abrasion, as well as warm, moist areas like the vulva, perineum (the piece of skin between the vagina or penis and the anus), scrotum, upper thighs, buttocks, underarms and lower back.

Auto-inoculation (self-infection) can occur by transferring the virus from one part of the body to another through contact with an active lesion—by touching a sore and then touching another part of the body (this can happen through masturbation, and vibrators and sex toys can also carry the virus). Herpes infection in the eye can lead to serious complications, including blindness. HSV can also be transmitted non-sexually through contact sports, where skin may become scrapes and then come in contact with another’s exposed herpes sore.

Transmission of herpes during childbirth can cause serious problems to the baby, including death.

Many people don’t know that they can transmit the herpes virus to a sexual partner even if they don’t have any symptoms. Many people don’t know that they can transmit the herpes virus to a sexual partner even if they don’t have any symptoms. This “subclinical” or “asymptomatic viral shedding” is a cause of much distress to those who are infected. Without symptoms, many people are unaware that they have herpes. It is estimated that around 80% of infections occur while there is asymptomatic shedding.

Anna Wald, MD, one of America’s leading researchers on herpes, published a study in the New England Journal of Medicine in March 2000 in which she looked at genital shedding of HSV in subjects who, when tested, had antibodies to HSV-2 yet reported having no history of genital herpes. She compared these subjects to a similar group of subjects with symptomatic HSV-2 infection. The rate of HSV shedding in the two groups was remarkably similar.

Suppressive therapy in patients with frequent recurrences reduces viral shedding and may reduce transmission to the partner even with such therapy, it is possible to spread the virus to others. No antiviral medicine has been proven to eliminate the transmission of herpes.

High levels of HIV have been found in herpes sores, making it easier for people with active herpes infections to also transmit HIV to their partners. Transmission of HIV in serodiscordant couples (one has HIV, the other doesn’t) is more likely to occur if the infected partner has frequent herpes recurrences—even more so if that partner is not on highly active antiretroviral therapy (HAART).

While the widespread use of condoms may offer some protection from transmitting herpes during anal and vaginal intercourse, the areas of skin not covered by the condom aren’t protected.

Prevention
Genital herpes is one of the most common STDs in the world, and there is a rising rate of infection in the general population. According to the U.S. Centers for Disease Control and Prevention (CDC), more than 500,000 new cases are diagnosed each year in America. The CDC also estimates that less than 20% of cases are currently identified. The majority of people infected with genital herpes either do not know or admit that they have the disease. Due to the lack of data on herpes, it’s widely accepted that statistics are underestimated.

Studies have indicated that having a higher number of sexual partners is associated with an increase in prevalence. Studies have also shown rates of herpes infection to be higher among women than men, and higher among African Americans than among other ethnic or racial groups in America.

Considering that genital herpes infections are at epidemic levels, it is quite shocking that there are no public health campaigns, not even routine screening, for herpes at STD clinics in Canada.

Genital herpes and HIV
The wide spread of HSV into the global population preceded the spread of sexually transmitted HIV. There is growing evidence of the connection between the two viruses. Early in the HIV epidemic, persistent herpes infection was often a first sign of HIV infection. The
majority of people with HIV/AIDS (PHAs) have genital herpes—estimates range anywhere from 58% to 81%. Outbreaks in PHAs are often more frequent and severe (larger lesions, last longer and spread over a larger area) than in HIV negative people. Also, studies indicate that viral shedding occurs at a higher rate in PHAs, and this is further increased in those with low CD4 counts. PHAs with seriously weakened immune systems can also experience outbreaks on internal organs, such as the brain, intestines, esophagus and lungs.

Genital herpes seems to accelerate HIV infection. According to the December 2002 Journal of Infectious Diseases, recurrences of HSV raise the blood level of HIV (viral load)—HIV replicates faster, causing an increase in disease progression. And, vice versa, the suppression of HSV leads to a drop in the HIV viral load. For this reason, daily suppressive therapy is usually recommended to PHAs with frequent herpes outbreaks.

Some PHAs with herpes experience severe outbreaks of one or more of the herpes viruses—genital herpes, shingles, CMV— when they begin HAART. This is because during immune reconstitution (the rebuilding of the immune system) low-lying infections can become active.

Herpes during pregnancy

Having herpes does not affect a woman’s ability to have a baby, but the possibility of passing the infection on to the baby can be a concern. The risk of transmitting herpes to a baby (neonatal infection) appears to be higher when the mother is infected for the first time while she’s pregnant (rather than if she acquired herpes before the pregnancy). Studies also indicate that HSV appears more likely to harm a baby if the mother has an outbreak at the time of delivery; in such cases, a Caesarean section is often performed. If a recurrence happens earlier in the pregnancy, the fetus rarely appears to be affected.

Neonatal exposure to HSV can be the result of asymptomatic HSV shedding. Some studies have indicated that as many as 60% to 80% of mothers whose babies became infected had no signs or symptoms of genital herpes at the time of delivery.

Doctors and midwives often suggest that pregnant women who are HSV positive take suppression therapy during the few weeks prior to delivery. The limited studies that have looked at using acyclovir at this time have found no toxicity to the babies.

Herpes infection in infants can be life threatening. Half of all babies infected with herpes develop severe neurological damage, mental disorders or death. The best results are seen with early treatment, before the virus spreads to the central nervous system or internal organs.

Treatment

Herpes infections are treated with antiviral drugs, such as acyclovir (Zovirax), famciclovir (Famvir) and valacyclovir (Valtrex). Treatment should be individualized to suit each patient’s needs.

“Episodic treatment” treats outbreaks when they occur. High-dose aggressive therapy taken for seven to 10 days at the first sign of symptoms shortens the duration and severity of outbreaks.

“Suppressive treatment” is ongoing daily therapy that’s usually recommended if outbreaks are frequent or especially bothersome.

Some PHAs who have regularly recurring outbreaks take the commonly prescribed (or lower than) suppressive dose, and then increase it when they feel prodomal symptoms (like itchiness or pain, which indicate an outbreak is about to occur). Some doctors do not recommend this approach as they feel it could create resistance to the drug.

The incidence of acyclovir-resistant herpes in PHAs is increasing. It is commonly treated with IV ganciclovir or foscarnet. Oral antiviral suppression is then continued after completion of the IV treatment. Cidofovir (Vistide) has also been shown to be effective at treating lesions that don’t respond to acyclovir.

Nutrition

Studies have shown that the amino acid L-lysine inhibits HSV, while the amino acid L-arginine promotes HSV activation. Some people have found that a diet that emphasizes foods with a higher lysine-to-arginine ratio and minimizes foods with a higher arginine-to-lysine ratio helps keep herpes in check. This is an approach that naturopathic doctors advise.

Try to avoid foods that have a significantly higher arginine-to-lysine ratio (and the total amount of arginine is high), including:

- chocolate
- nuts
- seeds
- peas

Try to eat more foods that have a significantly higher lysine-to-arginine ratio, including:

- fish
- meat
- dairy products

A comprehensive list of the lysine/arginine ratio of common foods, calculated using data from the U.S. Department of Agriculture, is available on some of the websites listed below.

Some people also report good results from lysine supplementation, however, studies have indicated that supplementation alone without the avoidance of food high in arginine has shown inconsistent results. HIV nutrition expert Lark Lands, PhD, supports the diet focus on internal organs that are higher in lysine and avoiding those higher in arginine, but he cautions against the long-term use of lysine supplementation, as it can create a deficiency in other amino acids.

Katherine Ota (not her real name) is a stoic hostess to numerous members of the herpes family.

Sore Sides: Herpes on the Web

International Herpes Management Forum
www.ihnm.org

The American Herpes Foundation
www.herpessfoundation.org

HIV and Hepatitis.com
www.hivandhepatitis.com

search for “herpes”

Antopia H network
www.goherpes.com

Herpes Support on America Online
www.members.aol.com/herpesite

The International Herpes Alliance
www.herpessalliance.org

(Clinique Medica pacifique)

The Phoenix Association
www.torontoherpes.com

Herpes Support on America Online
www.herpessite.com

www.hepatitis.com

Herpes Alliance
www.herpessalliance.org

Management Forum
www.ihnm.org

People Web Ring
www.raccoon.com/herpes/index.html

Your Online Resource to Herpes & HPV
www.herpessite.com

American Social Health Association
www.ashastd.org

(see the 3rd edition of Managing Herpes: How to Live and Love with a Chronic STD)

Clinique Medica l’Actuel
www.cliniqueACTUEL.com
HIGHLY ACTIVE ANTIRETROVIRAL THERAPY (HAART) has worked wonders for most PHAs, improving health and prolonging lives. But side effects can spell HAART—and heart—trouble. For example, many HAART users, particularly those on protease inhibitors, develop elevated levels of fats—cholesterol and triglycerides—in the blood. These, along with other factors (see sidebar), can increase the risk of damage to your heart and blood vessels that supply blood to the heart and brain. This is called cardiovascular disease (CVD).

The most common CVD condition is atherosclerosis, a narrowing and hardening of the arteries. Fats and other substances accumulate in the lining of the artery, forming plaques which can grow big enough to block the artery or break off into clots that travel to other parts of the body. They can obstruct blood vessels to the heart, causing a heart attack; to the brain, causing a stroke; and to the legs, making it difficult to walk.

Here are some heart-felt nutritional strategies shown to help keep lipid levels—and the overall danger of CVD—in check:

**EAT HEARTILY**

**Don’t chew the fat.** Dietary fat directly affects both the type and amount of fat in your blood, so check food labels and pick lower-fat products. Avoid partially hydrogenated fats/oils and greasy, fried and fatty foods. Baked goods, fast foods and snacks (chips, cheezies, crackers) tend to pack lots of fat and cholesterol.

**Choose healthier fats** like olive oil, canola oil and nuts. Limit saturated fats (in dairy and meats) and trans-fatty acids (in margarine and processed foods). Meat, dairy, egg yolk and shellfish also contain lots of cholesterol.

**Increase omega-3 fatty acids,** found in fish and flax. Eating fatty fish (canned tuna, cod, halibut, herring, salmon, sardines) at least twice a week has been shown to benefit heart health. Six to 10 grams of omega-3 fatty acid supplements a day (usually salmon oil or a blend of fish oils) can reduce triglycerides. Lower the dose if these supplements cause diarrhea or unpleasant burping. Flax seed or oil is a vegetarian source of omega-3.

**Fill up on fibre,** especially soluble fibre like psyllium (Metamucil), oats and legumes (dried peas and beans), to reduce cholesterol absorption. Legumes are also a healthy alternative to animal sources of protein, which are generally higher in fat and cholesterol.

**Try more soy products** such as tofu, soybeans and soy milk. They’re high in phytoestrogens, which reduce the risk of CVD if you eat enough of them (about 25 grams of soy protein a day—four glasses of soy milk or about 225 grams, or 8 ounces, of tofu).

**KICK THE HABIT**

**Limit alcohol** to a couple of drinks a week—booze boosts triglycerides. You may have heard that wine is good for the heart, but not necessarily so if you have high triglycerides to begin with.

**Get help butting out** because smoking is one of the most powerful CVD risk factors.

**Quit cocaine,** it promotes CVD and may increase your danger of heart attack.

**Have a HEART**

Diana Johansen helps you stay out of ticker trouble

**RISK FACTORS for CVD**

- Heredity (do your mom, dad or other close relatives have CVD?)
- Getting older
- Being a guy (men have an increased risk of CVD)
- Taking HAART
- Pre-existing diabetes that is not well controlled
- Abnormal lipid levels—high cholesterol or triglycerides
- High blood pressure
- Being overweight and/or having fat buildup in the belly
- Smoking

**SUPPLEMENT YOUR SUPPLY**

Some complementary therapies can interact with your meds, so evaluate them carefully before taking them.

**Antioxidants,** such as vitamin C (500-1000 mg) and vitamin E (400-800 IU), may help slow down atherosclerosis by reducing oxidative damage in blood vessels, which speeds plaque growth.

**Flavonoids,** found primarily in fruits and vegetables (especially colourful ones), help your health flourish and protect against heart disease. It’s better to get your flavonoids from food (which also delivers other health benefits) than supplements.

**The B vitamins**—B12, B6 and folate—lower homocysteine levels in the blood. High homocysteine has been linked to heart disease risk.

**Nicain,** a B vitamin, reduces triglycerides and LDL cholesterol and increases HDL cholesterol. However, niacin isn’t for everyone: The required dose can cause flushing and itching. Nicain can also promote insulin resistance, so you shouldn’t use it if you’ve got high blood sugar. If you’re on protease inhibitors, consult your doctor before using niacin—Pis can raise blood sugar, and in some cases, niacin may make this worse.

To get to the heart of the matter, there are lots of things about your family history and health profile that you can’t change. But you can lower your overall CVD risks by adopting a heart-healthy lifestyle. Sometimes changing your diet can be rough, especially if you have multiple nutritional problems. A registered dietitian can help you develop the plan that’s right for you—and help keep you from breaking that heart.

Diana Johansen, RD, is a clinical dietitian at the Oak Tree Clinic, which is a part of the Children’s & Women’s Health Centre of British Columbia. For more info on cardiac concerns, see CATIE’s Practical Guide to HIV Drug Side Effects at www.catie.ca/sideeffects_e.html.
Feeling down and out? Don’t deal with it all on your own... the following services are here to lend a helping ear.

NATIONAL
Canadian Mental Health Association
phone: 416.484.7750
fax: 416.484.4617
e-mail: national@cmha.ca
To find an office in your province, click on www.cmha.ca and go to “OMHA Locations.”

BRITISH COLUMBIA
Mental Health Information Line
phone: 604.669.7600
toll-free: 1.800.661.2121

ALBERTA
Alberta Mental Health Board
crisis line: 1.877.303.AMHB (2642) www.amhb.ab.ca
Alberta Mental Health Self Help Network
phone: 780.452.1930
toll-free: 1.866.452.1933
e-mail: admin@selfhelpnetwork.org
www.selfhelpnetwork.org

SASKATCHEWAN
HealthLine
toll-free: 1.877.800.0002
tty: 1.888.425.4444
www.gov.sask.ca
Registered nurse available 24/7 for health advice or info.

MANITOBA
Klinic Community Health Centre
toll-free: 1.888.322.3019
www.klinic.mb.ca
24-hour crisis line provides counselling, support and info.

ONTARIO
Centre for Addiction and Mental Health (CAMH)
phone: 416.595.6111
toll-free: 1.800.463.6273
www.camh.net

NEW BRUNSWICK
CHIMO Crisis Line
phone: 506.450.HELP (4357)
toll-free: 1.800.667.5005
www.revire.org
Accessibale 24/7, 365 days a year.

Government of New Brunswick
Family and Community Services
toll-free: 1.800.442.9799
www.gnb.ca/

P.E.I.
Island Helpline
toll-free: 1.800.218.2885

A 24-hour, bilingual, anonymous phone service that provides info, support or help in a crisis.

NOVA SCOTIA
The Self-Help Connection
phone: 902.466.2011
e-mail: info@selfhelpconnection.ca
www.selfhelpconnection.ca

NEWFOUNDLAND & LABRADOR
Mental Health Crisis Line
1.888.737.4668

Newfoundland and Labrador AIDS Committee
1.800.563.1575

YUKON TERRITORY
Mental Health Services
toll-free: 1.800.661.0408, ext. 8346

NORTHWEST TERRITORY
AIDS/HIV Information Line
1.800.661.0844

Crisis Telephone Line
Call collect: 0.867.872.4133

NUNAVUT
Health and Social Services
867.975.5713
toll-free: 1.800.663.5738

Mental Health & Family Services
phone: 867.975.5713

Alcohol and Drug Information Line
1.800.661.0844

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