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- + 5 PHAS DEFINE QUALITY OF LIFE
- + DO-IT-YOURSELF AROMATHERAPY
- + COOKING WITH WHOLESOME GREENS

the Positive Side

HOLISTIC HEALTH INFORMATION & VIEWS



Canadian AIDS Treatment
Information Exchange

Réseau canadien
d'info-traitements sida

Inside:



RONNILYN PUSTIL



SEAN HOSEIN



SHADDIE

Welcome to the 2nd “new and improved” *Positive Side* (PS), a Canadian magazine for people with HIV/AIDS (PHAs). In putting this publication together, we relied on the input of some incredible people, many of whom you’ll hear from in this issue.

When it comes to getting the most valuable, practical HIV-related info, where do you go? We’re talking about the juicy tidbits, the meaningful morsels – the stuff you just can’t find in a fact sheet. Looking for tips on how to handle troublesome side effects or advice on how to adhere...who ya gonna call? Newly diagnosed and down in the dumps? Who can best empathize? A new romance in your life! When is it time to disclose and how?

Let’s face it, for the most part, it’s fellow PHAs who are in the know about such things. And that’s where PS goes to get the goods you’ll find in these pages. The value of the grapevine is one of the operating assumptions behind PS. The PHA grapevine is made up of people *living* with HIV/AIDS speaking from *real-life* experiences – which is why it’s such a wealth of health information and views. “Where do I sign up?” you may ask. Chances are, you’re already part of it. But if you feel like an outsider, you can start to open those lines of communication right here and now.

PS takes a holistic look at life with HIV/AIDS, touching on all the aspects of your health that need nurturing: physical, mental, emotional, spiritual and sexual. Our main message? There may be some things in life that are beyond your control, but there is lots you can do to make the best of living with HIV.

For instance, Jim Wakeford (*on the cover*) has found that marijuana reduces his nausea and anxiety while increasing his appetite and helping him sleep. (Yes, he definitely inhales.) If that doesn’t fly with you, Wakeford’s passionate account of his fight for the right to grow marijuana for medicinal use is profoundly inspiring. Be sure to check out the sidebar for related resources. Don’t miss Evan Collins’ “Patients are from Venus, Doctors are from Mars,” chock-full of practical advice on building a healthy relationship with your doctor. As both a PHA patient and a physician, this doc knows what’s up! (Sorry, we couldn’t resist.) And Montreal naturopath Carole Durand describes her experiences bringing complementary and alternative therapies into an AIDS hospice. To catch some of the energy she brings into her work, try her do-it-yourself aromatherapy recipes for a boost.

Also in this issue: Nutrition expert Diana Peabody reveals “13 Ways to Love Your Liver.” HIV treatment guru Lark Lands, who wrote “The 10 Commandments” in the last issue, is back with “The 7 Deadly Sins.” Plus, in the spirit of the season, Mama Rossi cooks up a storm with greens (no marijuana recipes...sorry).

Do you like to pet? You’re not alone. Pets are one subject that came up repeatedly while working on this issue. Writer River Huston waxed poetic about her Yorkshire terrier Buddy. Jim Wakeford just couldn’t leave home without his cat Kiri. Two of the PHAs in Chatty CATIE, when discussing quality of life issues, sang the praises of their pooches. Michael Weinstein and Andrew McGregor, on the back page with their pup PeeWee, say that having a dog has benefitted their lives in many ways. All this anecdotal info shows what numerous studies have confirmed: Pets can help you feel better – psychologically, emotionally and physically. As someone who just got my first dog (*see photo at top*), I can vouch for that! So, for all you animal lovers, we included some Web resources for safe pet guidelines. Or should we say, safer? Just kidding.

We want to hear through the grapevine from YOU...so drop us a line via snail mail or e-mail (positiveside@catie.ca) with your feedback and ideas or a letter to the editor which may be printed in the next issue. If you missed the last PS, you can read it at www.catie.ca/positive.nsf. The next issue is dedicated to women, so if you want to contribute in any way, let us know as soon as possible.

And, of course, don’t forget the other branches of CATIE’s grapevine. By becoming a member (free for PHAs! see back cover for details), we’ll send you your choice of treatment info to keep you in the loop.

Ronnilyn + Sean

PS. Have a wonderful summer! May you pick only the sweetest grapes.

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the Positive Side

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A List of Things

I Could Have Used When I Found Out
I Was Positive on 5.15.90

I am going to need a storage space, no,
a warehouse would be better,
somewhere large enough to hold
the shock and later to fit
in the anger, make that
rage.

I will smile and cope the best
I can as everyone asks,
“Does this mean you are just HIV
positive or do you have AIDS?”
I will need a place to put my emotions
as I calm you —
you being mother, father, daughter, son,
friends, lovers.

I will need skin as thick as the doctors',
as each and every one will ask me,
“How did you get it?”
and even thicker skin if I am thinking about
dating or disclosing.

I will need an interpreter to help me understand
the language of treatment, activism, disability
HAART, NNRTI, AZT, PI, NGO, STI, CD4
this language will need to become second nature
so I can understand
what is expected
then I will need a hefty supply of *No*
No, I will not be a guinea pig,
No, you cannot talk to me that way,
No, you cannot have one more resident look
between my legs,
No, I need to see a doctor not a nurse,
No, I can't volunteer, you have to pay me,
No, I have not found your savior,
No, I am not the face of AIDS,
No, I am not OK.

I will definitely need people who will
never tell me it is going to be OK
OK is over new game

I will need to gather all the reserves
each of us is born with
venture into that place reserved
for all those people
in the one moment before
they got hit by the bus

I am chosen now I need to decide victim/survivor
I will need lots of water, green grass, love,
cookies and milk, naps, small animals,
time to myself, sex (yes, you can still have it),
friendship, a full life, hope, faith,
forgiveness and a boost to get to that place where I am able
to cut the ties that have bound me my whole life
I get a chance to let go
because I have been given a glimpse
of the horizon in three little letters: *HIV*.

—River Huston

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

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The **7** Deadly SINS

by Lark Lands

FOR THOSE WISHING TO LIVE LONG AND WELL WITH HIV

1 SIN #1: Thinking the disease is over. It isn't. When you reach the point where it's appropriate, HAART (highly active antiretroviral therapy) can certainly suppress the virus, restore at least some lost immune function and slow disease progression, but it is by no means a final and complete answer. Issues of drug resistance and side effects make long-term use of HAART very problematic. For long-term good results, *all* aspects of the disease must be handled appropriately. This means doing everything possible to slow disease progression and prevent symptoms with good nutrition and other non-drug means. And, if you're on HAART, it's important to protect yourself from side effects of the drugs.

2 SIN #2: Ignoring the nutrient needs that both the disease and the medicines create. Whether or not you're taking antiretrovirals, your body is fighting an ongoing battle. It needs higher levels of nutrients to do that. You can't power the body's immune response or build replacement immune cells without the nutrient building blocks. You need to consume:

- good levels of protein
- good levels of unrefined complex carbohydrates (brown rice instead of white; whole-grain breads, crackers, cookies and pasta instead of those made with nutrient-poor white flour)
- lots of fresh fruits and vegetables
- moderate amounts of good fats every day (mono-unsaturated fats like olive oil are best; avoid the partially hydrogenated oils found in margarines, shortenings and many baked goods and snack foods. Read the labels!)

■ lots of healthful liquids (water, juices, teas — not chemical- and sugar-loaded junk drinks)
That's how you power your body to keep up the immense battle against HIV. Numerous studies have shown that disease progression is faster in people with low levels of nutrients, so remember, nutrients are one of your best weapons against HIV. (Always make sure that the food you eat and the water you drink is safe.)

Nutrients can also help prevent or reduce the side effects and toxicity of medications while improving their absorption. You can help your body handle all the pills you're taking by giving it good nutrition, lots of healthful fluids, appropriate supplementation and plenty of liver and kidney support.

■ **With liver-toxic drugs:** Consider L-carnitine (or L acetyl-carnitine), and the nutrients that maintain glutathione levels in the liver — alpha-lipoic acid, vitamin C, vitamin E, N-acetyl-cysteine (NAC) and L glutamine. Depending on drug interactions (check!), silymarin (milk thistle extract) may also be useful.

■ **To help with kidney stress:** Drink lots of water throughout the day. Aim for a large glass every hour or so, especially each time you pop your pills.

Don't forget that nutrient supplementation can often help reduce or possibly eliminate HIV-related symptoms such as fatigue, skin problems, diarrhea and gas, memory loss, neuropathy and more. In order to manage a difficult disease long-term, you need to feel good!

3 SIN #3: Ignoring your intestines. If your intestines aren't working properly, you won't absorb drugs or nutrients well. The results can be serious nutrient

loss, wasting, and malabsorption of drugs — which can lead to lowered effectiveness and increased development of drug resistance. Use the nutrients that help heal and maintain the intestines, including zinc, vitamin A, B vitamins and especially L-glutamine. Natural anti-inflammatories may also help; possibilities are ginger, quercetin and other bioflavonoids, and essential fatty acids found in flaxseed oil or fish oil.

4 SIN #4: Ignoring instructions on taking drugs correctly.

You've heard this before but we'll say it again: If you're on HAART, medications must be taken very consistently, as per the precise dosage instructions. "Drug adherence" means: Never skip doses and always take your drugs exactly as prescribed and directed (with or without food, with lots of liquid, before or after a meal, etc.). This is terribly important to improve absorption and prevent toxicity and side effects. If you skip doses or take drugs improperly, effectiveness goes down and resistance goes up. *Remember:* Doing everything to eliminate side effects can help you adhere to your drug regimen because you won't be getting the miserable symptoms that make you not want to take your pills!

5 SIN #5: Ignoring the maintenance of muscle mass that's crucial for survival.

Wasting is still killing people. Monitor your body's status with regular weight measurements and bioelectrical impedance analysis (BIA). If either weight or muscle mass begins to decline, address it aggressively. For both men and women, it is critical to test testosterone levels and use hormone replacement therapy, where necessary, to maintain lean tissue and, a nice side benefit, your sex drive and mood. Women may also need female hormone replacement. For people with any level of serious wasting, recombinant human growth hormone (Serostim) may be very important to prevent the loss of muscle mass that keeps you alive. And exercise, especially progressive resistance exercise like weight training, is crucial for building and maintaining muscles, which contain a large proportion of your body cell mass. Maintaining your body in these ways not only promotes survival but also helps you look, function and feel better.

6 SIN #6: Thinking that reducing viral load fully and quickly restores immune function.

If your immune cells were ever below the normal range before you started HAART, you may not have speedy or complete immune restoration even when CD4 counts go

back up. Even though the evidence for immune cell restoration after a period of time on HAART is encouraging, the specific time frame for this is unknown and may vary widely between individuals. Studies have shown encouraging results when people discontinue either maintenance therapies (for an infection like CMV or cryptosporidiosis) or prophylactics (against common opportunistic infections), indicating that the body's immune ability may have returned, if not fully, at least enough to control or prevent some infections. However, until there are better tests for assessing the return of immune function, it will be impossible to know precisely who is protected from which particular infections.

Optimal nutrient status is crucial for the best results. The thymus gland that programs T cells is very sensitive to nutrient deficiencies; cell expansion requires nutrients to build and maintain the cells; and just maintaining immune response, in general, requires good nutrient status.

7 SIN #7: Failing to manage this disease properly, day in and day out.

The good news is: You've got much better weapons now in the fight to live long and well with HIV. The bad news? It's a lot of work that isn't likely to decrease anytime soon. You have to:

- eat the good diet,
- handle the hormone problems,
- do the exercise,
- take the drugs precisely,
- protect the body from infections, and
- take the nutrients that are necessary to provide protection against disease effects and drug side effects; help prevent disease progression and infections; rebuild damaged tissue and replace cells; and prevent symptoms.

As you do that work, try to keep the optimistic hopeful outlook that programs you for survival. We're not talking about doing all this for the next 10 minutes. We're talking about every day for the rest of your, it is fondly to be hoped, long and happy life. **ⓧ**

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. She has presented keynote addresses to many large AIDS conferences in North America and is the science editor of *POZ* magazine. For her fact sheets and treatment information summaries, go to www.larklands.net. The articles she has written for *POZ* are available at www.poz.com.

- To discuss your personal needs, naturopathic doctors can be located through your provincial naturopathic association, or see your medical practitioner.
- For much more in-depth info on eliminating drug side effects, see CATIE's *Practical Guide to HIV Drug Side Effects* (coming soon!). For more info on nutrition, see CATIE's *Practical Guide to Nutrition* at www.catie.ca/ng.nsf.

Living well — what the pros call “quality of life” — is the best revenge on HIV. But it can be hard work for PHAs, who tend to have a lot on their plate: diarrhea, neuropathy, lipo...and all the other medical minutiae that come with taking handfuls of pills every day. Even if you're not on meds, the many issues to deal with — from addiction to rejection to chronic infection — can make quality of life seem impossible. Aren't you overjoyed that AIDS is now a “chronic, manageable disease”? Hey, kitten, it's better than the alternative.

Chatty CATIE asked 5 PHAs from across Canada to define quality of life and reveal what they do to get it.

Kim Johnson, 31

Provincial peer network coordinator, Voices of Positive Women
Diagnosed with HIV: 1996
Viral load: 19,000
CD4 count: 220
Toronto, Ontario



From struggling with addiction to losing everything I owned to being diagnosed with HIV to giving birth to my son, I've become far less limited in my definition of quality of life. I used to say that all I wanted was to be free (I was in jail at the time). Then I discovered that prison had very little to do with bars and more to do with my ideas. To define quality of life would be to make finite what I've come to realize is infinite: *Freedom from the inside.*

Here's what I know: *Whatever you put into your life is what you will get back.* Quality of life is not about time and space so much as it is about the moment. *My life is a series of moments* — some good, some not so good, but they're mine and I'm free to do whatever I choose with them. If you catch me in a certain moment, I may have a lot to complain about, but the truth is, all is well and *I am truly grateful to be alive.*

If I struggle with things beyond my control, I tire quickly and my energy seems wasted. If I point a finger at other things as the source of my pain, anger or frustration, I do so at a great cost. I will miss the moment. I may miss my son's first day of school — not because I'm not there but because I'm *not there.* Living with HIV can be unnerving. I've thrown my hands up and yelled, “OK, how much time do I have? I have a lot to do, dammit!” It was a long road that I trudged to be here and to be, of all things, a mother. What a waste to miss any of it.

I eat well most of the time. *I take supplements.* I do my own vitamin B₁₂ injections. I sing all the time. I laugh and play a lot. I smile at life as often as possible. *I meditate.* I have the privilege of working with the greatest women in the world. I constantly remind myself where I've been and where I'm headed so as not to be stuck in either place and miss out on right now.

John Arenburg, 44

Support coordinator, AIDS Coalition of Nova Scotia
Diagnosed with HIV: 1985
Viral load: below 50
CD4 count: 1,085
Halifax, Nova Scotia



Quality of life is living my life as I want to live it, being happy and healthy. To do that, I have to have a *positive attitude* and not be judgmental. Being judgmental is a negative response to life.

I work hard. I try to not create stress in my life. *I keep up with my meds.* Actually, I just went off them, but taking them didn't interfere with my quality of life because I didn't have any side effects.

The AIDS Coalition of Nova Scotia has been a big contributor to my quality of life by being supportive to me over the past 13 years. I was 23 when I finally came to terms with being gay, and then, whammo!, at 25 I was HIV positive. It took me awhile to come to terms with that, and I did so with support from this ASO. Just knowing that there was somebody who could relate to me was very important. To this day, I still get the support I need here, through the other staff and our members. Some of our members who come to see me don't realize that they actually help me too. Working here also gives me the opportunity to give back to my community what that community has given to me.

Even though I have HIV and I work with other PHAs, it's not the first and foremost thing in my life. If a person is consumed with being HIV, it's not healthy at all. *I don't define myself by my HIV* or by the fact that I'm gay. I'm John Arenburg, and I'm proud of who I am as an individual.

You can eat healthy and take your meds and all that, and that does help your quality of life, but I think more important is *how you feel inside.* If you're dedicated to yourself and you love yourself, you're better able to love others and share that. *Knowing that you are loved is so important.*

Maggie McGinn, 45

Executive director, Living Positive
Diagnosed with HIV: 1992
Viral load: 180,000
CD4 count: 580
Edmonton, Alberta



How do I define quality of life? *If I feel good.*

What makes me feel good? *I attend my 12-step meetings.* I yell and scream if I feel like it, and I listen to other people yell and scream. I made a choice of *not using or drinking at all,* and I haven't for 10 years. I'm taking better care of my health and my emotions, rather than burying them under drugs and alcohol.

A really important piece to me around quality of life is that *I'm nonjudgmental* and I surround myself with people who won't judge me and who will take me at face value. *One of my favourite sayings is:* “Your opinion of me is none of my business.” Sometimes, though, I still sort of sweat under the armpits when I do things that I'm worried people will judge me about. But I do them anyway because, at the end of the day, it's me living with my conscience and peace of mind.

I probably wouldn't still be here if I hadn't had my kids, *Stephanie and Jessica.* They gave me the sense of responsibility I needed to take care of myself. *They're my will to live and stay well.* Stephie crawled up my knee when she found out I was positive and said, “Mommy, I don't want you to die.” And I said, “Stephie, I don't want your mommy to die.” It's not about I don't want *me* to die; I don't want *Stephie's mommy* to die. I've still got my mommy. She's 77, and she's still my mommy, whether she likes it or not.

Michael Linhart, 44

Former prison coordinator, BCPWA
Diagnosed with HIV: 1991
Viral load: 176,000
CD4 count: 80
Vancouver, British Columbia



It's quite simple. To me, quality of life is the ability to go about a relatively normal life without too many inconveniences as a result of meds or medical conditions; to be able to *live on my own without assistance,* to take meds that will allow me to do the things a 44-year-old would do.

Anything that got in the way of me being able to take care of and *play with my dog, Shasta,* would interfere with the quality of my life. She's a purebred American pit-bull — a 55-pound lap dog — an inspiration and a motivation.

My friends and personal interests keep me up and moving around rather than focused on the fact that I'm taking massive cocktails and I have diarrhea and don't really have the energy. *Mental headspace* is a really big thing in my quality of life.

Because *I'm co-infected with hepatitis C,* I went on ribavirin and interferon treatments last year. About three months into it, I got pneumonia and nearly died. At the time, I was on a five-drug HIV cocktail and the hep C combination, and I had virtually no quality of life.

In prison, I fought tooth and nail for virtually anything and

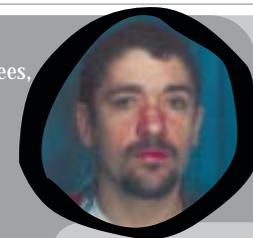
everything that was available outside. Achieving quality of life in prison is a lot more challenging. You don't have the same access to general standard of care. It was very difficult to get a proper diet or things that help with side effects. Most often, you can't even get additional food so you can take your meds properly, the way they're prescribed. Plus, there's no access to adequate vitamins or supplements. I basically used the negative aspects of being positive and taking meds in an *advocacy capacity* to enhance my quality of life and, hopefully, to make a difference in other people's. That became much of the premise of my job at BCPWA.

To PHAs in prison, I'd like to say: Quality of life is based on how you perceive it, and then in your determination to pursue it in a positive, pro-social manner. It's what you're willing to fight for. There are grievance systems you can use and community agencies out there that will help with advocacy issues.

The value that we're able to put into and take out of each and every day is far more important than the number of days we have. So, to use a Latin cliché, *Carpe diem.* Seize the day. Get the most from it that you can.

José Sousa, 40

Waiter; works on many committees, including Canadian HIV Trials Network and COCQ-Sida
Diagnosed with HIV: 1985
Viral load: 14,000
CD4 count: 310
Montreal, Quebec



Quality of life is where *the good things in my life outweigh the negative;* that the benefit of my antiretroviral therapy outweighs the negative side effects. Although I'm currently not on antiretrovirals

because I'm in a structured treatment interruption study, I still take approximately 60 pills a day — *various vitamins and minerals* — which I do for my quality of life.

I try not to overwork. If I do, it's usually in my HIV-related work, which contributes to my knowledge. That, in turn, contributes to my health, which in the end leads to a better quality of life. I watch comedy programs on TV almost every day because *laughter contributes a lot to my life.* So does my dog, Porto (named after the Portuguese sweet fortified wine), because the unconditional love I get from him makes me go to bed with a smile on my face.

Green Acres

Marijuana. Pot. Weed. Ganga. Maryjane. Herb. Folk medicine. Whatever you call it, JIM WAKEFORD is fighting for the right to grow it for therapeutic uses and he won't give up until he's won. Put that in your pipe and smoke it.

I AM ONE OF THE LUCKIEST MEN ON THE FACE OF THE PLANET, despite the fact that I've lived knowingly with HIV since 1989 and with full-blown AIDS since 1993. Born in 1944 in Regina, Saskatchewan, land of wheat, big sky, Northern Lights and farms, I've outlived countless prognoses. At 57, I've put my affairs in order often enough to know they never will be. I currently weigh 123 pounds and I know my days are numbered.

Some people say the grass is greener on the other side of the fence. Well, the grass on my side is pretty green. I live on the beautiful Sunshine Coast and devote much of my time to growing marijuana — the most magical plant I've come across in my search for relief from AIDS and its accompanying blood tests, pokes and prods, and the nasty effects of the chemical soup of prescription pills I consume daily to survive. Though I have just over 200 T cells and an undetectable viral load, my face is gaunt. I have no body fat. Veins run like bloated rivers up and down my skinny arms and legs. My gut has a life of its own, changing shape at will. I have lipodystrophy. Small wonder that I seek relief where I find it.

In 1996, I began my first four-drug combination — Crixivan, d4T, ddI and 3TC. I added vitamins and supplements to my health care regimen, which I continue to use when I can afford them. That year, to address my wasting, I also started using marijuana, both smoking it as well as using in teas, brownies and soups. Marinol, a synthetic pill form of THC (the active ingredient in marijuana) available by prescription, and its sister drugs caused waves of nausea and vomiting. Mostly I smoke buds and inhale, because this lets me control the dosage. Controlled consumption of marijuana allows me to

manage many of my symptoms. I believe I'm alive partly because of my purposeful use of this herb.

Two years after starting combination therapy, I spent several weeks in and out of Wellesley Hospital in Toronto. I was taken off my meds when doctors realized that they had caused wasting so severe that a Hickman line was inserted in my chest to give my bowels and gut a break. I was fed by total parenteral nutrition, through a tube, 12 hours a day for two months. After the line was removed in the spring of 1998, I had to relearn how to eat, which I did with the help of remarkable friends who brought me meals and love while I fought to reclaim my life.

Taxing exemptions

Seven gorgeous green girls — strains of marijuana sativas, indicas and hybrids grown from seeds I planted in November 2001 — are flourishing in the flowering stage in my garden in rural British Columbia. They are so legal and illegal at the same time, it breaks my heart. This will be my eighth crop of marijuana. I've lobbied for six years and fought civil litigation for the past four — all for compassionate access to marijuana for therapeutic uses. It has cost over \$125,000. I don't qualify for legal aid.

Marijuana has been used for centuries recreationally and medicinally. It was demonized in North America by the 1937 American Marihuana Tax Act, effectively prohibiting production of hemp and marijuana. Fast-forward to the 1980s, when we needed compassion most, the Reagan administration instead declared war on drugs in North America, including marijuana.

In 1999, I thought I'd resolved my pot problems. On May 10, represented by my lawyer, Alan Young, I won the >

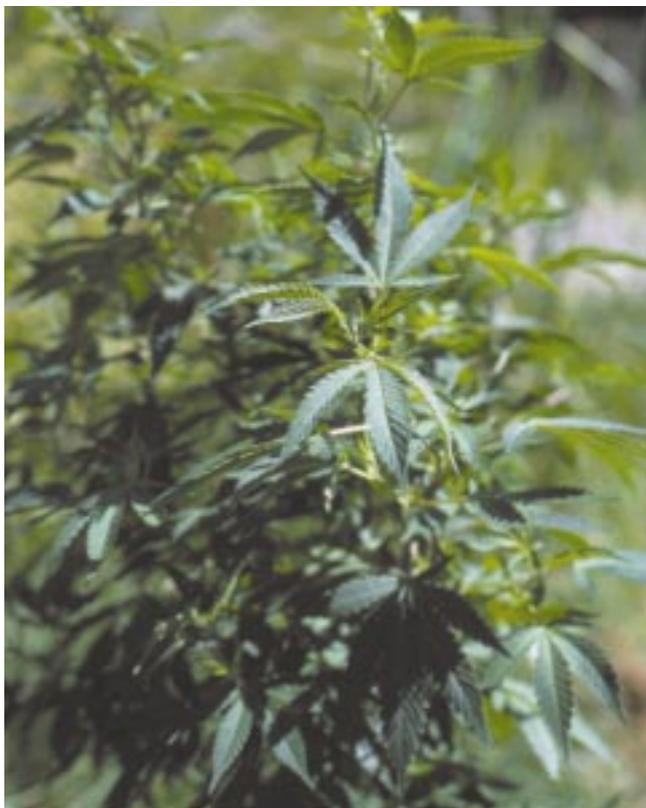


constitutional right in the Ontario Superior Court to use and grow marijuana for medicinal purposes. The federal government began granting exemptions in June 1999, through the office of Allan Rock, then Minister of Health. I was issued one of the first two section 56 exemptions in Canada. Rock got good sound bites for his “compassion,” while his bureaucrats created a fatally flawed process. There is no legal supply of marijuana in Canada.

I launched an appeal for a legal supply and caregiver immunity. I lost, twice. Regulations proclaimed in July 2001 pit patient against doctor against bureaucrats. Application forms require doctors to “prescribe” dosages in grams. Doctors can’t do that. They don’t know what we’re smoking. They observe and chart our reported use, that is, the doctors who cooperate. I’ve found it helpful to be able to talk to doctors about my care, including marijuana use, but I don’t rely on them for supply or assistance. I’ve recently sought leave to appeal to the Supreme Court of Canada, my last hope.

Right without remedy

By the year 2000, some of my friends with AIDS began to get exemptions. It was like being all dressed up with nowhere to go. We had no supply and no seeds or clones to start gardening. My first exemption had no limit to the number of plants I could grow. Subsequent exemptions, including those issued to my friends, limited us to seven



plants each. I brought up the idea of pooling exemptions. Five agreed. I went to British Columbia and met a breeder who donated clones, baby pot plants, which I flew home and grew on my Church Street balcony. Our crop was bountiful, our exemptions well exercised, or so I thought. We had safe, clean, affordable, high-quality strains of marijuana to fight malnutrition, chemotherapy side effects, anxiety, fatigue, depression, exhaustion and the occasional feeling of hopelessness at the relentlessness of AIDS. We had choice. I called it the Cannabis Research Cell. It was wonderful while it lasted.

Attempts to collaborate with underground growers and keep the strains led to police involvement and lost crops and strains. We’d soon be without medicine. I began to resent the exemption process, the police, dealers, crooks and politicians. And so I decided to bridge the gap between exemptees, police and government.

I rented a farm just north of Toronto, in Udora, Ontario, and invited the chiefs of the RCMP, OPP and York Regional police to visit after the “grow system” was set up. I was hoping for their support. They wouldn’t come. Days later, two officers from drugs and vice in York region paid a visit. I showed them my grow room, which at the time was a 20-by-20-foot room with dozens of donated cuttings and sprouts. Three or four plants were flowering in a closet. I told them about our illnesses, our exemptions and my plans to establish The Farmer Jim Society, a nonprofit registered charitable organization, to grow marijuana, herbs and vegetables for people experiencing catastrophic illness. I am working to establish a way for the poor to have equal access to marijuana. Like Valerie Corral, founder of the Wo/Men’s Alliance for Medical Marijuana (WAMM) in Santa Cruz, California, I want to take the money out of the access problem (check out her website at www.wamm.org; great recipes!). Like Valerie, I give marijuana to sick people. The police took notes and left.

Then it got hot. Two days after the police visited the farm, the phone rang. I was being busted. I made it out to the farm in time to be arrested and charged with production, possession and trafficking. I watched in horror as police slaughtered our little green girls. They left seven plants. I wept.

I was arrested twice more in Ontario for similar “offenses” before I decided to pick up my pussycat and move. The planned May 27, 2001, planting ceremony in Udora, to which I’d invited 500 guests, turned into a closing ceremony. I gave the remaining pot plants to people with exemptions and moved the rest to another farm in Ontario that was dedicated to growing marijuana for exemptees. That night, thieves stole all the donated lights, nutrients and grow equipment.

Broke and exhausted, I sold most of my furniture and moved out here last August. After nearly 40 years in Toronto and several careers, including working at Casey House Hospice, I now live on a farm with Kiri, my 17-year-old Siamese cat, and a group of creative people. We dwell communally, committed to learning to live with the rhythm of nature.

Up the creek

Spring has arrived in Robert’s Creek and our world is bursting with life. We are committed to reclaiming and reshaping five acres of land into gardens of bamboo, herbs, vegetables, fruit trees, paths and ponds. Our shared service to Mother Earth allows us to live largely from her bounty. We reuse, recycle, repair, buy second-hand or go without. The land is lush, and we help keep it that way. We call it permaculture. It’s a way of life, not just gardening.

Our fruit trees are bountiful, our blackberries huge. Our chickens lay orange yolk eggs that taste like “buttah.” Rich, black, oozing soil brimming with worms has been layered into large sculpted mounds. Among the green vegetables are flowers, including nasturtiums, to garnish meals. In the Zone One gardens, just outside the front door, we grow beets, broccoli, cabbage, kale, leeks, lettuce, onions — food we use every day. Herbs grow on layered rock formations. Zone Two gardens, a short walk away, yield corn, potatoes and yams. Growing my few pot plants in a zone of their own scarcely makes a dint in the gardens here. It is one plant among many.

I’ve barely begun to learn about the healing properties of this amazing plant. But I’ll tell you what I do know: The sativa strains I grow yield a cerebral “high,” while the indica strains provide more of a “body stone.” Sativas are excellent for daytime use if I’m nauseous because they don’t make me sleepy. They increase mental alertness and are remarkable for appetite enhancement. Indica strains relax me, reduce anxiety and help me sleep. Basically, I use marijuana to fight wasting, not to get wasted.

Waste lines

My 13-year battle with AIDS has led me to luscious green marijuana gardens and a lot of thorns. I’ve survived wasting, crooks and cops, threats, debt, exhaustion, anger, depression, diarrhea, thrush, rage and grief — unfathomable grief at the deaths of hundreds of my friends. AIDS still shocks me.

My adverse drug reaction to my meds in 1998 resulted in an unplanned drug holiday until June 2000 when I began a new combination — 3TC, d4T, abacavir and efavirenz. I resumed life chained to a drug regimen with nasty side effects. I continue on that therapy and I’m rigorously compliant, even as my skeleton pushes at my skin through my limbs, face and spine. I am shrinking and I can see my body without me, my raw skeleton, the body I’ve loved and lived >

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OH CANNABIS

Bowing to pressure from the Ontario courts, the Canadian federal government has set up a system to grant the legal right to grow, possess and use marijuana for medical reasons. These “Marihuana Medical Access Regulations” went into effect July 2001, replacing the “section 56 exemption” system.

All necessary forms and instructions are available from Health Canada’s Office of Cannabis Medical Access:

www.hc-sc.gc.ca/hecs-sesc/ocma/ or **1.866.337.7705**.

Most PHAs need a medical specialist (not “just” a primary care physician) to complete one section of the application form. (Although you’re allowed to use a non-specialist if they say you’ll probably die within a year. Seriously.)

This office does not supply marijuana, only the legal right to use it. You have to grow it yourself or designate someone to grow it for you. Many people use buyers clubs or “compassion centres” as their source of marijuana, even though they are illegal.

Compassion centres sell clean, safe marijuana to anyone with written proof of a relevant medical condition such as HIV. Some of the larger compassion centres are:

- BC Compassion Club Society, www.thecompassionclub.org
- Toronto Compassion Centre, www.torontocompassioncentre.org
- Cannabis as Living Medicine (CALM), www.cannabisclub.ca
- Montreal Compassion Club, www.clubcompassion.org

The Community Research Initiative of Toronto (CRIT: **416.408.1041**) will soon be enrolling patients in a small pilot study of smoked cannabis for appetite stimulation and weight gain.

Other websites to check out:

- www.medicalmarihuana.ca — how to use the federal regulations, a listing of all the compassion centres in Canada and lots of other useful stuff
- <http://cannabislink.ca> — Canadian trends, info and resources connected to cannabis
- www.mpp.org (Marijuana Policy Project) — an American site (if you think it’s bad here!) with tons of info and current news
- www.maps.org (Multidisciplinary Association for Psychedelic Drugs) — the latest medical marijuana research

— Derek Thaczuk



Die Well

A Montreal AIDS hospice gets CAT-ty with aromatherapy and more *by Carole Durand*

FOR MORE THAN A DECADE, a Montreal AIDS hospice has been improving the quality of its residents' lives with complementary and alternative therapy (CAT). Maison d'Hérelle grew out of a pilot project originally supported by the City of Montreal and the Ministry of Social Services to help people with HIV/AIDS (PHAs) retain their independence. From the outset, in light of the limited medical means of the period, CAT was particularly welcomed and went a long way toward helping to instill hope in the residents, who initially had come simply to die with dignity. That's part of the mission of the hospice — to create an atmosphere that respects and honours each person's individuality as they live out their lives according to their own convictions, while also respecting the common well-being. And, so, it was primarily in response to residents' evolving needs that CAT was introduced.

The initial experimentation focused on massage therapy and the results proved conclusive. In addition to

creating a stronger bond between staff and residents, massage therapy helped lessen certain types of pain that didn't respond to medication. The comfort provided by touch also became an important part of the care. Improvements in both the physical and psychological well-being of residents, while sometimes only temporary, were observed as a result of this contact.

There has been steady progress in the development of complementary approaches at Maison d'Hérelle. In 1993, primarily because of my training in naturopathy and aromatherapy, I was hired to develop this discipline further. A committee was created to promote the development of CAT and to train staff and volunteers. In the beginning, we had to progress slowly in order to respect our coworkers' and the community's concerns about CAT. We had already introduced a few plant extracts, such as tinctures (made from a plant soaking in alcohol for some time to extract its active ingredients) and herbal tea infusions, to treat minor issues like digestive problems, colds and flus. Essential oils are highly concentrated substances that are very powerful, so we started off using them almost exclusively on the outside of the body for massages. Although we proceeded with caution, our colleagues often cast a skeptical glance in our direction...especially when they saw us apply cabbage compresses on bedsores to extract pus and aid in the healing process. *Mon Dieu!*

Herbal essence

Gradually Maison d'Hérelle became a reference point for Montreal PHAs interested in CAT; hospitals and local health community centres now frequently ask for our recipes. Through our use of CAT, we've obtained good results for many problems — from infectious diseases (herpes, bronchitis) to skin problems (dermatitis, rashes) to pain management. We've formulated our own recipes for aromatherapy tonics and herbal creams that can improve a person's well-being and help him or her deal with various AIDS-related problems. Already grappling with a wide range of medications, the residents see in these approaches an opportunity to regain some control over their health and reduce some of the undesirable effects they're experiencing — without having to take more pills.

The main approaches used by the hospice team are: phytotherapy (herbal therapy), aromatherapy (the art of healing with essential oils), homeopathy, nutritional supplementation, energy healing (such as therapeutic touch, Reiki and massage), art therapy, colour therapy and music therapy. These services are provided primarily by staff and volunteers. Four of the employees have specific training in CAT; they recommend different approaches to the residents as well as prepare aromatherapy and herbal mixtures. The other team members apply and provide the therapy to the residents. A reference book created by the committee with information on treatments available for different pathologies is used as a support tool for the team.

As a naturopath, the opportunity to develop and try out treatments that can benefit the residents is a privilege. Although I practice various approaches, I have a preference for *scientific* aromatherapy. More than simply a science of smells, this approach concerns the biochemical composition of aromatic plants and their physiological effects on humans. Although not appropriate for use in all situations, the results are often truly amazing when it comes to treating many kinds of infections, as well as regulating and rebalancing the body. Essential oils used in aromatherapy are administered on the skin via massage and can also be inhaled or taken orally (diluted in oil or in capsules). We also make suppositories for respiratory disease and problems related to the genital and anal area.

Now I'd like to let you experience the therapeutic effects of aromatherapy yourself with a couple of effective recipes I've tried with the hospice residents and my private-practice patients:

DO-IT-YOURSELF TONICS

These aromatherapy recipes are used frequently at Maison d'Hérelle and have proved excellent at increasing energy and reducing side effects that cause anergy (absence or lack of energy). These tonics are very concentrated, so use them carefully. Because of their strong effects, one must apply essential oils with a certain rigour and have some basic knowledge about them or ask for some professional support. Because essential oils are expensive, they are often diluted with solvents, so make sure to buy oils that are labeled with the Latin name and the chemotype. You can buy them at most health food stores.

Adrenal gland tonic – tonifies the adrenal glands, which is involved in stress reduction

- 5 ml *Picea Mariana*
- 5 ml *Pinus Sylvestris*

Mix together and rub 5–10 pure drops on the area of the adrenal glands (just above the kidneys; on your lower back) 2–3 times a day.

General tonic – works on different levels of fatigue to increase digestion, equilibrate the nervous system and increase vitality; also used for mild depression

- 2 ml *Cinamomum Verum*
- 2 ml *Mentha Piperitas*
- 2 ml *Thymus Satureoides*
- 2 ml *Ravensara Aromatica*
- 2 ml *Melaleuca Alternifolia*
- 90 ml first cold press olive oil

Mix together and take 1/2 teaspoon 3 times a day for 30 days. Because this tonic is taken orally, it's especially important to buy high-quality therapeutic essential oils.

Here are some brand names you can trust:

- Pranarom, distributed by Robert & Son
- Heliolab, distributed by Heliolab
- Sanoflore, distributed by Sanoflore 

Besides working at Maison d'Hérelle, Carole Durand collaborates with the Canadian Health Network to increase the visibility of CAT in Quebec. She writes for CPAVH's *Le Point de VIH+* and gives workshops throughout Quebec to promote the use of CAT for AIDS. She is currently working on a clinical trial that will evaluate the efficacy of essential oils in immune reconstitution. If you have any questions or need support, you may contact her by e-mail at carolenat@hotmail.com.

Patients ARE FROM VENUS Doctors ARE FROM MARS



How to build a healthy relationship with your doctor

by Evan Collins

IN SOME WAYS, LIVING WITH HIV IS ALL ABOUT RELATIONSHIPS. When you first test positive, relationships with lovers, friends, family and coworkers are called into question as you consider whom you can tell and count upon for support. One of the most important people in your life becomes your doctor, especially if you choose to take HIV medications. Since we are forced to spend a lot of time with our docs — and allow them to see intimate sides of ourselves — how we relate to them becomes critically important.

Unfortunately, many people remain dissatisfied with their health care providers. It can be hard to get an appointment, we wait a long time to see them, and then they're often so rushed that there is not enough time to adequately address our concerns. Frequently, we don't like how they communicate or we feel they pay more attention to our lab numbers than to ourselves. We may have philosophical differences or they may be ignorant, perhaps intolerant, of our lifestyles or the alternative approaches we wish to integrate into our care. Finally, although doctors are increasingly trained to be more sensitive and collaborative, there is still a long tradition of the physician being in control of the knowledge and treatments, which can get in the way of a good relationship.

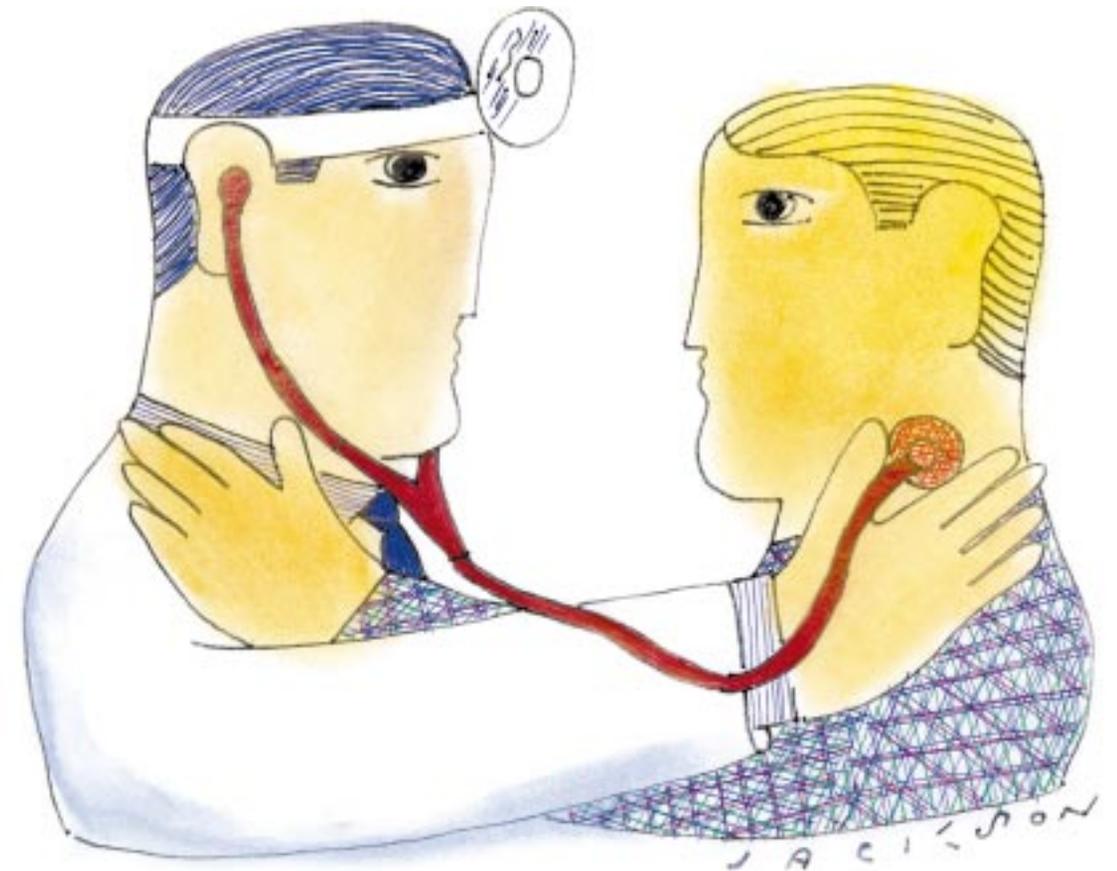
As both a doctor and a person living with HIV/AIDS (PHA), I have thought a lot about these issues. Despite problems within the health care system, it *is* possible to build a healthy relationship to optimize our health. This

entails choosing the right physician to match your needs and personality, educating yourself, and working on better communication over time. Every relationship — whether with your partner, mother or health care provider — has its problems and needs constant effort to keep it working well.

*Can't live with 'em,
can't live without 'em:
A history of medical paternalism*

From the time of the ancient Greeks, there was a dynamic of parental authority in the medical relationship. Hippocrates himself said: "Obey your doctor and you will start getting well." Early Western medicine was closely aligned with religion and doctors often assumed the authority of God. As medicine developed a scientific tradition based on principles of anatomy and physiology, the authority was strengthened by a knowledge base that was in the exclusive domain of the doctor. Over time, this was made more exclusive by the legislative control of the training and practice of Western practitioners over healers from other traditions, such as midwives and naturopathic physicians.

This dynamic of medical paternalism started to change in the 1960s with the counterculture and questioning of all institutions. A signal event was the publication of the revolutionary *Our Bodies, Ourselves* by the Boston Women's Health Collective in 1970. This book challenged



how medicine was practiced and taught women to become more involved in their own health. The women's health movement started to rewrite the rules of being a patient and laid the groundwork for PHAs.

When AIDS was first recognized in 1981 as a new condition concentrated in the gay male community, medical professionals were as baffled as their patients. As knowledge progressed, patients often knew more than their physicians from having shared information with each other. AIDS service organizations (ASOs) sprang up with a mandate to empower PHAs with information about AIDS and its treatment, and the skills to read and critically appraise scientific research were developed and shared. Over time, PHA power and influence grew and, along with it, gradual changes to how AIDS research was

conducted, how governments regulated new drugs, and how medical care was provided by hospitals and individual practitioners.

Other influences that have changed the traditional doctor-patient role have included the rise in popularity of Complementary Alternative Medicine (CAM), the power of the Internet to keep us informed, and the new emphasis on communication skills in the training of physicians.

*Top or bottom:
What type of patient are you?*

Even though the authoritarian doctor-patient relationship has softened, not all health care providers are open to an informed patient who wants a say in

directing his or her own care. Even if a physician's heart is in the right place, he or she may not have the time to allow for collaborative decision-making. Additionally, different patients have different needs and expectations of how much they wish to be involved. A recent Ontario study on HIV and decision-making suggested that most PHAs want a shared role in decision-making but do not want to have complete autonomy in directing their care. Plus, people's needs change over time: A person early on in their HIV journey may need a physician who is more active, educational and assumes all the decision-making. As that person becomes more informed about HIV, he or she may need a different type of relationship with their doc, or a different doctor.

PHA seeking MD: Finding the right physician

What to look for in a physician? First of all — and perhaps most important — is someone who knows HIV. Ideally, they should have a large number of other HIV patients so they're forced to keep up to date. They should be interested in HIV by choice, not because they're stuck with you. Further, they should also communicate an acceptance of you and your lifestyle. This is especially critical when a patient wishes to use alternative approaches as a complement to their physician's medical care. At the very least, your doctor should be open to your use of alternative therapy and knowledgeable about any negative interactions it may have with your medications. Ideally, your doctor should be prepared to communicate with your complementary practitioner and work in a collaborative fashion. Ask friends or your local ASO for names of docs with a good reputation in the community.

More than anything, I hear PHAs talk about needing a doctor who pays as much attention to their personal lives as to their CD4 count and viral load — someone who takes into account their total quality of life instead of just a list of symptoms. Confirming this, a recent U.S. study assessed what aspects of the doctor-patient relationship related to overall satisfaction among PHAs. Most strongly correlated with satisfaction was: 1) patients who were comfortable discussing personal issues with their doctor; 2) patients who perceived their general practitioners as empathic; and 3) those who perceived their docs to be knowledgeable about HIV issues.

Most people's primary physician is a general practitioner (GP) or family physician. If this doctor has considerable experience with AIDS, he or she may take the lead in directing HIV care. If the doc, or you, is not comfortable with his or her HIV experience, you may see an HIV specialist who usually is an internist, an infectious disease expert or an immunologist. Although this person may handle things related to HIV, one should still have a GP who takes care of other things like colds,

flu shots and other non-HIV-related problems. A GP may also be the one who refers you to specialists for consultations and advice on handling other problems that crop up (for example, seeing a dermatologist or a cardiologist).

Ideally, the doctor you see should run an efficient office where you don't have to wait too long to get an appointment or cool your heels in the waiting room for hours. Even more important is the time you get inside the inner sanctum. Are appointment times ample enough to adequately address your concerns? Can you book longer appointments for when you have more in-depth concerns? A visit for a prescription renewal will require less time than an assessment for depression. Ask the office manager or nurse about how the office is run and about time issues; how do they handle after-hours problems and the need for last-minute appointments? The receptionist/office manager is often the power behind the throne, so a good relationship with them can be as important as one with the physician.

What's Up, Doc? Making it work

So, you've found a doctor who is taking new patients and he or she seems like a good person. Bonus! Now how to make it work? First and foremost, educate yourself as much as possible. In the HIV community, we are fortunate to have resources like CATIE that provide information about HIV and treatment options. Take advantage of the Internet (click on www.catie.ca), fact sheets, articles, newsletters, and books like CATIE's *Managing Your Health*. Attend lectures and workshops. Consult with treatment counselors at CATIE (dial 1.800.263.1638) and your local ASO. Knowledge really is power. Your doctor is a good resource for some of this info but by no means the only resource, especially given his or her time restraints. The more homework you do in advance, the more productive your time with your doc will be.

Be prepared to also educate your doctor. He or she may not be as up to date as you, especially regarding CAM. In most cases, your doctor will appreciate you filling him or her in. Bring along articles and leave them for your doctor to review. Also, each time you visit, bring a list of questions and issues you want to address. It will keep the visit organized and ensure that you don't forget anything.

Finally, try to be completely open with your doctor. Be up-front with issues relating to your lifestyle, substance use, adherence to medications, and anything else that is relevant to your health. Of course, one risks a judgmental response but tolerance is something you can work on. It is better for the management of your HIV that everything is on the table.

If your physician is not meeting your needs, there is certainly nothing wrong with firing your doc and finding a new one. Most doctors have a thick enough skin that they won't be offended if you transfer your care to someone else. Of course, this is a luxury that only PHAs in larger communities can afford. In many places, one can't even find a physician taking new patients, let alone one who is HIV-knowledgeable and has the right personal qualities.

Will you still love me tomorrow? Growing old together

Even if you've found the right doctor who meets your needs and you're working well together, as with any relationship there will inevitably be the occasional disagreement or problem. If you and your doc do not see eye to eye on some issues, it is not the end of the world. What's important is that you continue a dialogue, if necessary over a number of visits. You may also agree to disagree. Even in the face of conflict, try to communicate in a spirit of mutual respect.

I have underemphasized the role that our imperfect health care system plays in making a healthy doctor-patient relationship challenging. With growing cutbacks, pressures and inequities in the system, there will always be problems that beset even the best doctor-patient relationship. In the end, whether it be a problem in the system or in your relationship, what matters most is that you keep talking and trying to make it work. The HIV journey is a long one and your doctor is an important companion on that journey. 

Evan Collins, a former CATIE Board member is a person living with HIV. He works part-time as a psychiatrist in the University Health Network and as a physician at the Hassle Free Clinic, in addition to doing research related to HIV drug side effects. He is currently chair of the AIDS Committee of Toronto. As a patient, he is presently with his fourth HIV primary care physician and second Infectious Diseases specialist.

Patient's Bill of Rights

- You have the right to be treated with dignity and respect.
- You have the right to hope.
- You have the right to ask questions.
- You have the right to honesty.
- You have the right to a second opinion.
- You have the right to confidentiality.
- You have the right to up-to-date and balanced information.
- You have the right to refuse any therapy.
- You have the right to have all tests and treatment be done with your full informed consent.
- You have the right to your doctor's full attention.
- You have the right to get important information in person.

How to Get Along Famously

Pop artist Andy Warhol once said that in the future everyone will be famous for 15 minutes. Well, the future — complete with 15-minute-and-out-the-door doctor or clinic visits — is now. Here are **8 great tips for making the most of your doctor's 900 seconds.**

Remember: You are the star of your own production!

- Keep a notebook to jot down symptoms and side effects, including anything unusual to report from the bathroom. These are clues for better diagnosis and treatment.
- Make a note of anything going on in your life that's affecting your health.
- Have all official information and cards ready: insurance or health card; pharmacist name and number; medical charts, X-rays and lab results.
- Keep a list of all the drugs you're taking (including over-the-counter ones) and all the HIV drugs you've ever taken. Also keep track of which doses of your HIV meds you've missed. Adherence difficulties are nothing to feel guilty about, so let your doc know.
- Tell your doctor about any alternative or complementary treatments (herbs, vitamins, supplements) you're on. You may want to be prepared for some skepticism, but this isn't about his or her endorsement. It's an update. And it's important in order to check for any possible interactions between your medications and supplements.
- Keep a to-do list to check with your doctor: What prescriptions are you running low on? What "labs" do you need? What appointments do you have coming up? Do you need referrals (acupuncturist, therapist, herbalist, etc.)?
- Bring clippings about possible new drugs or treatment strategies to discuss.
- Bring something to read. They're always running late.

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13 Ways to Love Your

Liver

Diana Peabody brings you back from the liver's edge



YOUR LIVER IS ONE OF YOUR MOST IMPORTANT ORGANS — you cannot live without it. The liver is like a processing plant for the body. Raw materials — such as nutrients, alcohol, herbs and drugs — are absorbed from the gut to the liver where they are processed, transformed, stored, detoxified and transported to the rest of the body. The liver works hard to keep your cells nourished, to process medications that fight HIV and other infections, and to detoxify hazardous substances. In order to keep working at its best, your liver needs to be well nourished and protected from damage.

People with HIV and AIDS (PHAs) sometimes have additional stress on the liver due to the toxicities of some antiretrovirals as well as hepatitis and/or substance use. One early warning sign of liver distress or damage is an elevated level of liver enzymes, which can be detected by blood tests. All PHAs, especially those on antiretrovirals, should have their liver enzyme levels monitored on a regular basis, since many people remain unaware of liver damage until it is quite advanced. Liver disease can lead to malnutrition, which can then accelerate liver damage.

Whether you're trying to protect a healthy liver or help your liver get better, the most important thing is to stay as well nourished as possible. The following tips can help you keep your liver in good working order:

- 1 **Try to avoid alcohol altogether if you have liver disease (hepatitis).** It is extremely toxic to the liver and evidence shows that boozing causes liver disease to progress faster. Alcohol can also worsen the side effects of antiretrovirals and increase the chance of developing liver damage. Try to cut out recreational drugs for the same reasons.
- 2 **Make sure that you are vaccinated against hepatitis A and B,** and avoid situations that place you at risk for getting hep C, such as sharing needles and nasal instruments like sniffers, straws and bills.
- 3 **Achieve and maintain a healthy body weight.** Being too thin or too fat is not good for the liver.
- 4 **Maintain generous stores of lean body mass (muscle tissue).** Both HIV and hepatitis can cause wasting of muscle tissue. In your health regimen include regular exercise that builds muscles (such as walking, running and weight training).
- 5 **Get enough protein.** Protein provides building blocks for new cells, tissue repair and the immune system. For people with HIV and/or hepatitis, the recommended daily intake is 1 to 1.5 grams per kg body weight (a 70 kg person requires 70-105 grams of protein per day). Try to get 2-3 servings of lower-fat meats (such as lean beef, fish or chicken) and alternatives (such as peanut butter and tofu), and 2-3 servings of lower-fat dairy products or soy milk each day. In very advanced liver disease, protein intake may be modified or restricted because of a condition called encephalopathy (brain fog). However, do not cut protein unless absolutely necessary, and never do it without your liver doctor's advice. Also consult with a dietitian.
- 6 **Get enough calories to spare protein.** If you do not get enough calories each day, protein will be diverted from its essential protein duties in order to make energy.

Most people living with HIV and/or hepatitis require 30-40 calories per kg body weight (a 70 kg person needs 2,100-2,800 calories per day). You can check your calorie intake at www.caloriescount.com.

- 7 **Choose more whole grains, fruits and vegetables** (such as beets and artichokes) rather than processed foods, sugar and sweet drinks. Some HIV medications can cause insulin resistance, which makes it difficult to use nutrients properly, especially sugars. Eating less simple carbohydrates (sugars and starches) helps insulin work better, which keeps blood sugars in the ideal range and may prevent diabetes. Besides, these foods are much more nutritious for you.
- 8 **Eat a moderate amount of dietary fat and emphasize "good" fats** like those found in olive and canola oils, nuts and seeds rather than saturated fats like dairy fat and animal fats. Moderate means cutting back on high-fat, fried and greasy foods, but not restricting fat too much because it provides valuable calories.
- 9 **Take a multivitamin to prevent deficiencies.** Do not take high doses of vitamin A or carotenoids (beta carotene) if you have liver disease, as these can be toxic to the liver.
- 10 **Do not take iron supplements unless prescribed by your doctor to treat an iron deficiency.** If the liver is not working well, iron can build up and be toxic to the liver. High levels of iron also feed some bacteria that cause infections and may interfere with interferon treatments for hepatitis. If your liver is functioning well, a multivitamin containing iron is fine. If not, choose one without iron.
- 11 **Supply extra antioxidants to the body.** Antioxidants are compounds that protect the body from highly active molecules called free radicals. If levels of free radicals build up, they can damage tissues and accelerate the destruction of the liver in people with hepatitis. This process can cause the depletion of glutathione (GSH), a major antioxidant in the liver cells. Daily doses of vitamin C, vitamin E and selenium will provide basic antioxidant coverage. N-acetyl cysteine (NAC) and alpha-lipoic acid are also antioxidants that help make GSH and are thought to have a protective role in the liver. (See the sidebar for a list of daily doses of antioxidants.)
- 12 **S-adenosyl methionine (SAmE) is an amino acid supplement reported to have liver healing properties.** Studies of HIV negative patients with liver disease showed improved liver enzyme and bilirubin (a waste product) levels; less fatigue, jaundice and itching; as well as improved quality of life. The suggested dose is

usually in the 800-1,600 mg range. However, there is little information about possible drug interactions with HIV medications, and test-tube studies show that SAmE promotes the growth of PCP (*Pneumocystis carinii* pneumonia). This supplement may emerge as an important therapy for the liver but little is known yet about its use in HIV disease. So if you are considering using SAmE, discuss this with a liver specialist (hepatologist).

13 **Herbal therapies, such as milk thistle (silymarin), have been widely used to treat the liver and other health problems.**

Be aware that some herbs are toxic to the liver and some interact with antiretrovirals. Get informed about the benefits and risks of any therapies you are planning to try and consider your unique situation. You can look into drug interactions on your own with a great resource at www.aidsmeds.com. At this site, click on "Check Your Meds." It will allow you to enter all your medications + nutrients + herbs + various foods (like garlic or grapefruit, both known causes of certain interactions), and then give you information on all the possible known interactions between these things.

The bottom line? Your liver is affected by everything you ingest, so be mindful about what you eat, drink and take as medications or supplements. Remember to always discuss any supplement or exercise plans with your doctor. Do your best to emphasize the things that promote health and minimize those that cause damage. If your liver is already damaged and needs some extra TLC, you should get more personalized nutrition advice from an HIV-savvy dietitian. We don't want to cry a liver over you! 

Diana Peabody, 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.

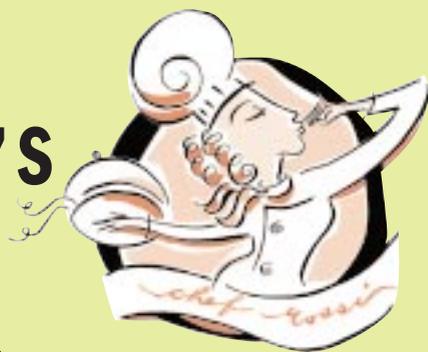
For more info on these and other supplements for liver health, check out CATIE's Supplement Sheets on antioxidants, selenium, vitamin E, NAC, alpha-lipoic acid and milk thistle, available at www.catie.ca or by calling 1.800.263.1638.

Daily dosage of antioxidants considered safe with potential benefit for your liver:

- | vitamin E — 400–800 IU
 - | vitamin C — 500–2,000 mg
 - | selenium — 100–200 mcg
 - | NAC — 500–2,000 mg (take with food to avoid gastrointestinal tract irritation)
 - | alpha-lipoic acid — 100–600 mg (preferably in an extended-release form; take on an empty stomach with fluids)
- Note:* Vitamin C doses greater than 2,000 mg may cause iron overload in a damaged liver.



MAMA ROSSI'S



Edible LOVE

Mama Rossi dishes out some green peace for summer

I AM SOOOOOOOO GREEN!

No, darlings, not jealous. No, not nauseous. Not rolling in money (*&^%\$ darn it!). No dearies!! I'm not an alien either... well, not that I'm aware of, but I *am* originally from the suburbs so you never really know and I do seem to have a strong pull toward glitter and glam rock, but don't get me started. No, my bodacious biscuits, I'm just gorgeously, grandly, gratefully green because I'm rolling in the steamy summer scene!! What, you never get a little giddy when the seasons change? Listen, there's nothing sexier than summer (hmmm, well, except of course for *moi*).

Really dearies! What a perfect time of the year to celebrate fresh, delicious, healthy produce. Can't you hear the asparagus calling? "Hi, it's me, asparagus! Can you come out and playyyyy? A little stirfry might be nice or just roll me around on the grill!"

I don't know about you lovely lettuce cups, but I'm ready for an all-you-can-eat green buffet! It's time to throw out those heavy winter stews and casseroles and dig into Mama Earth. Ouch! I said Mama Earth, not Mama Rossi!

The following are some perky, wholesome recipes guaranteed to have you seeing green and loving it!

LE MENU DU JOUR:
 I Three Greens in Heat
 I Easy Grilled Asparagus
 I Watercress, Mizuna and Baby Arugula Salad
 I Cucumber Kim Chee

THREE GREENS IN HEAT

Wash **collard greens**, **spinach** and **bok choy**; you'll want two bunches of each for a nice dish. Cut into pieces about the size of salad lettuce (a bit larger than bite size because they shrink to nothing after cooking).

In a huge pan, heavy-bottom pot or whatever you have, sauté a mess of sliced **garlic** in about two shots of **olive oil** over medium heat. The oil should really cover the garlic. Then add your collard greens, spinach and bok choy. After you've stirred your greens for a minute, toss in a shot or two of water to keep things nice and moist. Then cook and stir (I like to shimmy too) for 10 minutes or so, just until your greens are wilted but still a touch crunchy.

Toss greens into a bowl and mix with a sauce made up of about two shots of **soy sauce** mixed with two drizzles of **sesame oil** and one plop of **hot Chinese chili paste**. Season with **salt** and **fresh ground pepper** and serve. I like a lotta hot in my greens, but you can tone it down if you're shy.

EASY GRILLED ASPARAGUS

If you don't have an outdoor grill or stove-top grill, just use a heavy-bottom skillet. The trick is to get the thing so nuclear hot that it'll feel like a barbecue.

Trim your **asparagus** (your asparagus will tell you how much it wants to be trimmed; just break it off above the tough part, that's usually about an inch from the bottom). Toss asparagus in enough **olive oil** to coat them and then sprinkle to taste with **salt** and **fresh ground pepper**. That's it!

They're ready for fire. Just throw those babies on a medium-hot grill and cook until you see them turn bright green and get nice dark grill marks. Talk about sex appeal! Remember to pull them off while they're still crunchy or you'll be serving some really poopy gus.

Drizzle with **fresh lemon juice** and you're done. Easy and good.

WATERCRESS, MIZUNA AND BABY ARUGULA SALAD

Trim a couple bunches of **watercress** of excess stem (which is fancy chef talk for only leave about a bite size amount of stem on your greens), wash well and toss with an equal amount of washed **baby arugula** and **mizuna** (a salad green). You'll want a nice big bowlful because it's so yummy.

Make a refreshing dressing by mixing two drizzles of **fresh lemon juice** with one smidgen of finely chopped **fresh garlic** and a half plop of **Dijon mustard**. Then slowly whisk in about a shot and a half of **olive oil**, and season to taste with **salt**, **fresh ground pepper** and love.

Toss up your salad and you're good to go. If you want to get fancy you can garnish this with shaved **fresh parmesan** or crumbled **goat cheese**, but it's nice just the way it is and so are you.

CUCUMBER KIM CHEE

Kim chee or Kimchi (also known as Korean pickles) can be made out of everything from carrots and red radishes to jicama and the more traditional cabbage. I like cucumber for kim chee because it only takes one day of marinating, as opposed to the decade-long traditional kim chee recipes. I started one in the '70s and it's still not ready.

Peel two or three **cucumbers** (any kind is fine) and cut into rounds or ovals. Then toss generously in **Kosher salt** and leave in the refrigerator for one hour.

To make the kim chee dressing: Mix a handful of chopped **scallion**, one half **onion** diced, a plop of **minced garlic**, a smidgen of **minced ginger**, a few good pinches of **chili powder** and enough hot water to bring it all around into a sauce-like consistency.

Wash your salt off the cukes and drain them. Then toss them in your dressing and marinate overnight. You can marinate for as long as you want, even a day or two.

When ready to serve your cucumber kim chee, garnish with sliced **chives**.

Well, lettuce cups, there you have it, one small munch from the garden, one giant break for the cows. ♀



THE IMPATIENT COOK'S GLOSSARY

SMIDGEN: what fits between your thumb and forefinger without falling out

PINCH: a little less than a smidgen

SPRINKLE: a smidgen plus whatever usually falls out

HANDFUL: self-explanatory. But we're talking about a normal adult-size hand, not your toddler's hand and not Godzilla's hand

MESS: a heaping handful

PLOP: a little more than a tablespoon

DRIZZLE: sort of like two wet plops

DOLLOP: a heaping tablespoon or a plop and a half

SHOT: what you get in your shot glass if the bartender likes you

COFFEE-CUP-FULL: sort of like a cup only just a leeeettllleee bit more. Plus, when you're done, you can drink coffee out of it! Isn't that special.

Chef Rossi is one of the New York catering world's most vivacious personalities. When not cooking up a storm as the catering director, owner and executive chef of The Raging Skillet, a cutting-edge catering company known for breaking the rules, Rossi writes food and entertainment columns for various publications and is a featured guest on The Food Network. For a taste of Chef Rossi, check out www.theragingskillet.com.



DAAIR (DIRECT ACCESS ALTERNATIVE INFORMATION RESOURCES) www.daair.org/DAAIR/dp.NSF/pages/home

WE HAVE A SOFT SPOT FOR DAAIR, the not-for-profit buyers club for PHAs and their doctors looking to include complementary and alternative therapies in the treatment of HIV disease. Founded by long-term survivor and activist Fred Bingham, DAAIR, in its own words, “promotes self-empowered healing to help manage HIV/AIDS...through the use of scientifically researched nutrients, other natural therapies and mind/spirit practices.” In their 10 years of operation, the New Yorkers have amassed an encyclopedic knowledge — and inexpensive catalogue (though prices are in U.S. dollars) — of what’s hot on the herbal front. Call them toll-free — yes, even from Canada — at 1.888.951.LIFE (5433) for up-to-the-minute information about accessing non-approved therapies safely.

One downside of the DAAIR website is that much of the information was posted in the year 2000 and many items are simply not dated (undated entries on websites about HIV can be landmines for info seekers). So you’ll have to check with DAAIR if you wish to use its wonderfully comprehensive recommended protocols

— what to take and how much it will cost you — as a blueprint for your own treatment strategies against HIV/AIDS as well as lipodystrophy, neuropathy, chronic sinusitis and hepatitis. These plans are a great starting point, but you’ll have to do a bit of the legwork to keep things current. Still, you’ll find a lot at www.daair.org on the basics.

Click through the DAAIR catalogue and you’ll see that SB Normal Stool Formula (you can’t buy this at your average health food store in Canada), made from the sap of a tree found in the Amazon rainforest, can be used as a possible treatment for watery diarrhea. And if a practitioner touts a treatment, DAAIR’s catalogue entry will disclose any financial interests on the part of the person recommending it.

So, any complaints we have about the website are stated knowing that they’d do better if they had the resources and time to update it. Though it is well worth your time to check out www.daair.org, be sure to call before you take what you read as treatment gospel. 

—Kevin O’Leary

> continued from page 11

in, worked and played in. I feel thin. It hurts to sit on hard surfaces. None of my clothes fit anymore. My feet are no longer cushioned. I no longer hope for a cure.

But my life is richer with fine-quality marijuana. Nothing else relieves me from the bone-crushing fatigue or the feeling of having to puke and trying not to because it hurts too much and your mouth is full of thrush and you wonder how the hell you’re going to survive this time and AIDS feels so unforgiving.

Future growth

In April, I appeared in court, charged with possession for the purpose and trafficking. I pleaded not guilty. (Although the Ontario charges were withdrawn last October, I was busted again in November in B.C.) There will be a preliminary court appearance in September and I go to trial January 20, 2003.

The epidemic continues to horrify me, as my wasting fascinates me. I feel betrayed by the government and the courts for putting me in this Catch-22 situation. The arrests, the costs of setting up the farm in Udora and the move to B.C. have all taken a toll on my health and my pocketbook. I’ve never been poorer and never been richer. I have no money but I have people around me

who really care and who know the work has barely begun.

Hundreds of sick Canadians have been granted Ministerial exemptions — people with AIDS, multiple sclerosis, chronic pain, mental illness, spasm, arthritis, hepatitis, cancer. None have safe, clean, affordable high-quality strains of marijuana. Most are poor and can’t afford it. There is an office for cannabis medical access in the federal government, which has spent millions of tax dollars growing marijuana in a bunker in Flin Flon, Manitoba, from seeds confiscated by the RCMP. There is no distribution plan for any of it. I want sick Canadians to have choices of strains so we can begin to translate “Hey man, that was a blast” to “That strain helped me eat, or deal with nausea or spasms, or whatever the problem.”

A few months ago, returning from a trip visiting my supportive parents in Saskatchewan, I flew over the mountains and saw the green vastness of British Columbia, knowing that this is where I’ll continue the work. Marijuana must be legally available to Canadians who need or want to use it therapeutically. How lucky I am to be Farmer Jim, growing pot for pain, not for gain. 

If you want to contact Jim Wakeford, you can call 604.886.0030 or e-mail jimwakeford@dccnet.com.



Dog Day Afternoon

back page

Michael Weinstein, 49

Diagnosed with HIV: 1984 CD4 count: 340 Viral load: 7,450

Pet: Mack and I have been together for three years. Two years ago, we got a puppy, a Jack-a-Poo — part Jack Russell terrier, part poodle. Mack named him PeeWee, which is perfect — he's very hyper; if you recall the show *Pee-wee's Playhouse*, that's exactly what he's like. It's like *Pee-wee's Playhouse* every day in our apartment.

PeeWee has definitely changed my life for the better. When I'm sad or lonely, he always makes me very happy. There's not a day that Mack and I don't laugh; we have such fun with him. When I come home from work, he goes crazy when he sees me. It's nice to have an extra heartbeat in the apartment. He's there for 100% unconditional love.

I'm Daddy 1 and Mack is Daddy 2. Mack is more the disciplinarian; I'm more of the suck. I always give in, I can't help it. I spoil him.

Every day when I take my pills — approximately 40 a day — I'm reminded that I'm HIV positive. But ever since we got PeeWee, it seems that I just go to the cupboard and take my pills, and that's that. I don't really concentrate on it anymore.

Physically, I get a lot more exercise. It's a big responsibility — we have to walk PeeWee three times a day, take him to the vet for his shots, feed him, pick up after him — but it's never a pain. We take showers together and he absolutely loves it. I scrub him up and wash him down, and Mack towel dries him. We share the responsibility.

When we got him, we bought him a beautiful cage. He was in there for five minutes. The first night, he was crying. I couldn't take it; I told Mack to open the door. Ever since, he sleeps right between us. We're one big happy family. PeeWee is like the child I never had. We've had him since he was a puppy, we trained him and we're watching him grow up. He's 2 years old now. I want to see him grow up. I want to be there with him when he's older.

PHD pet peeve: The diarrhea from my meds. But I'm used to it now. I just go with it. I take Metamucil with my pills at night; it's a binding agent. It works like a miracle.

Andrew McGregor (Mack), 44

Diagnosed with HIV: 1999 CD4 count: 505 Viral load: undetectable

Pet: Michael bonded with the dog the first day we got him. PeeWee has brought a sense of wholeness to Michael's life, and hence, to my life. Having a dog makes you refocus on a few things, both personally and professionally, in a positive way.

When I'm not feeling well, like today, it's always nice to have the company of my dog. He's here with me, he knows through instinct that I'm not feeling well and he keeps good company with me. He's very sedate, much like I am right now. He knows that I can't and don't want to play in the fullness of how we normally play.

As we're learning not only in the science of HIV but in all illnesses, a dog contributes to a stress-free environment, and for that, having a dog can only benefit someone with HIV.

PeeWee is a great stress reducer. I can come home with a bad-ass attitude and all I need is five minutes of love and I'm fine for the night.

There's nothing better than coming home to PeeWee because he's as anxious to see me as I am to see him. A pet gives only the best of unconditional love. No human can ever fill that menu. A human strives to love unconditionally, but as we all know, that's not always the case. Nothing's better than a kiss from a puppy. PeeWee smiles for me when I greet him, and that's worth a thousand hugs and kisses.

Michael cannot say no to PeeWee. Michael does not know the word *no*; PeeWee has never heard the word *no* from him. In the first 12 months of PeeWee's life, I let him know who was boss. Now, it's just a matter of not even raising my voice much but just pointing a finger at him when he's out of line. It's

interesting, PeeWee has been able to divide his love equally between the both of us. I cherish that. PeeWee has enhanced our relationship. We treat him as though he was our son.

PHD pet peeve: The resurgence of my allergies and asthma. It's gotten worse in the last three years, since my HIV has been diagnosed and treated. My doctor says this is a result of a hypersensitive immune system. I use Claritin Ready Tabs for my allergies. My asthma is horrible all year round. When I'm having an attack, I have to back away from whatever I'm doing, try not to panic, and get to my puffer immediately. ⚡



Photography by David McIver

Resources:

Centers for Disease Control and Prevention

Preventing Infections from Pets: A Guide for People with HIV Infection www.cdc.gov/hiv/pubs/brochure/oi_pets.htm

PAWS (Pets Are Wonderful Support)

Safe Pet Guidelines www.pawssf.org/library_safepetguidelines.htm

Canadian Veterinary Medical Association

Pet Ownership and Zoonotic Diseases www.animalhealthcare.ca/care_guidesN2.asp

Surf's Up!

Trying to avoid the sun and heat of summer? Turn your fan on high and log on to the Net. Here are some must-surf websites.

The Canadian Harm Reduction Network

www.canadianharmreduction.com or 1.800.728.1293 Launched in February, this site is "the meeting place for individuals and organizations across Canada dedicated to reducing the social, health and economic harms associated with drugs and drug policies." Check out the electronic newsletter, *iCHIP* ("in Canada Harm is Passé"), extensive links and the Events page for a listing of harm reduction conferences.

The **Canadian Harm Reduction Conference** is taking place this November 22-24 in Toronto. For more info, click to <http://harmreduction2002.ca> or call 1.866.704.2990.

For a listing of other upcoming AIDS-related conferences in Canada and abroad, visit **The Canadian HIV/AIDS Clearinghouse** website and click on "News and Events": www.clearinghouse.cpha.ca (You can now order publications electronically, such as CATIE's newly reprinted *Managing Your Health*.)

The **13th International AIDS Conference** is taking place this July 7-12 in Barcelona, Spain. Be sure to check out upcoming *CATIE News* (www.catie.ca/aidsinfo.nsf/news) and *TreatmentUpdate* (www.catie.ca/tu.nsf) for the treatment buzz.

Develop your skills by clicking on the **CATIE** website: www.catie.ca/e/aso/develop_skills.html You'll find links to such gems as "An Introduction to Researching your own Treatment Information" by CATIE Librarian Tiffany Veinot; and "The ABCs of HIV Disease and Treatment," a training guide for HIV educators developed by the British Columbia Persons with AIDS Society (BCPWA).

Canadian Treatment Action Council (CTAC)

www.ctac.ca or 416.410.6538 What good is treatment info without access to meds? CTAC, a national organization directed by PHAs, promotes informed public policy and education, as well as awareness on issues that impact access to treatment and health care. Its newly launched website includes position papers, a quarterly newsletter, events calendar and more.

Canadian HIV Trials Network (CTN)

www.hivnet.ubc.ca/ctn.html or 1.800.661.4664 The latest HIV/AIDS clinical trial activity in Canada. The website provides info about CTN and non-CTN trials that are currently enrolling participants. You'll also find several publications, including a guide for people considering enrolling in a clinical trial and a model informed-consent form.

Canadian Aboriginal AIDS Network (CAAN)

www.linkup-connexion.ca or 1.888.285.2226 With CAAN's innovative "Linkup: An Aboriginal On-Line HIV/AIDS Information Network" users can download documents on Aboriginal AIDS issues that have been produced across Canada, chat with others, find out about upcoming events in the Aboriginal community across the country and more.



Mission: CATIE is committed to improving the health and quality of life of all people living with HIV/AIDS (PHAs) in Canada. CATIE provides HIV/AIDS treatment information to PHAs, caregivers and AIDS service organizations who are encouraged to be active partners in achieving informed decision-making and optimal health care.

This publication is available on-line, in French and English, at www.catie.ca, or by calling 1.800.263.1638.

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

The Canadian AIDS Treatment Information Exchange (CATIE) in good faith provides information resources to help people living with HIV/AIDS who wish to manage their own health care in partnership with their care providers. Information accessed through or published or provided by CATIE, however, is not to be considered medical advice. We do not recommend or advocate particular treatments and we urge users to consult as broad a range of sources as possible. We strongly urge users to consult with a qualified medical practitioner prior to undertaking any decision, use or action of a medical nature.

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HIV Positive?

Having trouble finding local resources?

Looking for treatment information?

Feeling overwhelmed?

CATIE is here for you. Let's talk.

Call anonymously: 1.800.263.1638

Speak to one of our knowledgeable Treatment Information Services Representatives about treatment questions or local resources in your area of Canada.

Visit the CATIE Web site: www.catie.ca

Over 20,000 people each month visit our Web site to read or download treatment publications, check our current news or to find links to other Internet sites with information about HIV/AIDS.

E-mail treatment questions to: questions@catie.ca

Use the privacy of e-mail to ask questions of our knowledgeable Treatment Information Services Representatives when it is convenient for you.

Become a CATIE member:

More and more HIV+ Canadians are joining CATIE as members to benefit by receiving monthly updates on treatment information by e-mail or regular mail. Visit www.catie.ca or phone **1.800.263.1638** to join.

