

# THE POSITIVE SIDE

HEALTH INFORMATION & VIEWS

SUMMER 2007  
VOLUME 9 ISSUE 1

SHE'S 30

Different issues,  
same boat

HE'S 60

## SHOWING COMPASSION

Medicinal pot for those who need it  
Plus: How to get it

## STICKING TO IT

Understanding adherence

## ASK THE EXPERTS

Gut reactions



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## EDITORS' LETTER

This is, as we often say here at *The Positive Side*, a magazine for, about and primarily by people living with HIV/AIDS. And we are reasonably successful, we think. Indeed, we are proud of the issues we discuss, the stories we tell and the writers and artists with whom we work.

And yet there is something too simple about this blanket statement. After all, the estimated 60,000 people in Canada who are living with HIV/AIDS come from all walks of life, every age, every region and every heritage. Indeed our audience is no less broad than the entire population of Canada.

Our cover image tells that story. It is keyed to two articles in this issue—one on positive youth, the other about positive seniors. Two distinct and discrete populations with different values, needs and outlooks. And yet the story these articles convey are very similar: in a time of change and evolution in the reality of HIV in Canada, perceptions, preparations and programs also must change.

First, as Laurette Lévy reveals in her article on AIDS and aging (page 8), there is so much still to be learned about the long-term physiological and psychological effects of being HIV-positive and on anti-HIV medications for extended periods of time. Second, the infrastructure needed to support an aging positive population—trained general practitioners and specialists (in gerontology, immunology and psychology), supportive living facilities and financial support—have only begun to be discussed. There is a great deal of work to be done.

The same can be said about youth in Canada—because at least half of all new cases of HIV in Canada are among youth. As Colleen Patterson reports in “The Truth about Youth” (page 12), we are not prepared. There is not enough funding for agencies to create the programs, environments and facilities youth need. Nor are there effective prevention campaigns specifically geared to youth that address their stunning lack of awareness of HIV and the risks of unprotected sex. There are many things that need to be done, but none is more important than a commitment that programs for youth be created with and by youth.

We hope, no matter who you are, that you find something of value in this issue of *The Positive Side*.

—The Editors

## THE POSITIVE SIDE

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# FROM THE FRONT LINES

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## NORTH

### Looking North for Answers

Most people in the southern part of this country know very little about northern Canada and the realities of life above the treeline. Southern Canadians' lack of awareness about the high hepatitis C and HIV infection rates among the Inuit community illustrates that point all too well. But now, with an announcement that **Pauktuutit Inuit Women of Canada**—an Ottawa-based organization “providing leadership, voice and excellence for the betterment of Inuit women, their families and communities”—has received a seed grant from the Canadian Institutes of Health Research, a much clearer picture should soon be available.

Indeed, public health experts have been profoundly concerned that the situation is dire. While there are few reliable statistics on HIV infection rates in the North, experts and some community leaders point to very high rates of sexually transmitted infections (from 9 to 125 times the national average) and alarming rates of teenage pregnancies (2.5 to 4 times the national average). Human papilloma virus (HPV) is also over-represented among the Inuit. According to a recent briefing, these elevated rates indicate a grave potential for the entry and spread of hepatitis C and HIV.

There are concerns, too, about stigma and discrimination against Inuit people living with HIV and hepatitis C, says Jeanette Doucet, manager of Sexual Health and HIV/AIDS Policy and Programs at Pauktuutit. “The lack of openness... often leads to isolation and ostracism for Inuit PHAs and can force them to stay in and hide their illness or flee to urban centres where they may access care and treatment. This isolation and transition, on top of a very aggressive and deadly illness, can be overwhelming for many.”

The project—entitled Strengthening Community-Based Approaches to HIV/AIDS Education, Screening, and Testing among Canadian Inuit Youth—is a partnership between Pauktuutit and

Dalhousie University and will begin preliminary community consultation in Arviat, Iqaluit, and Montreal to identify priorities. The result will be recommendations for the focus of future research and programming.

For more info, go to [www.pauktuutit.ca](http://www.pauktuutit.ca).

## PACIFIC

### Like Sea and Sky

Yin and yang. Positive and negative. Black and white. They say opposites attract, and it's true—just ask any happy couple that is serodiscordant (meaning one partner is HIV-positive and the other HIV-negative). But understanding our opposites can take a lot of work. And that's why the **British Columbia Persons with AIDS Society (BCPWA)** held its second of three pilot weekend retreats for serodiscordant couples in late May.

Building on BCPWA's 20-year history of offering healing retreats to clients, team member Neil Self says the goal of this new retreat is to strengthen, affirm and enhance the relationships of serodiscordant couples. Over four days, partners participate in guided sessions on communication and couple visioning as well as a massage workshop and social activities. There's also a seminar on HIV prevention and negotiating risk as partners become more intimate.

The couples also separate and do group work with participants of the same HIV status. “Some couples don't know a lot of people in their situation,” says Self. “It really helps them to

connect with others and share their experiences.”

Free of charge, the retreat is open to serodiscordant couples in British Columbia and attracts about equal numbers of same-sex and opposite-sex couples. For more information check out the BCPWA Web site ([www.bcpwa.org](http://www.bcpwa.org)) or call the retreat hotline at 1.604.893.2213.

## ONTARIO

### Help Seeking Help

Ever wondered where to find an AIDS service organization (ASO) that provides housing support in your area? Or how to get in touch with an ASO that offers



services in, say, Cree? You're not alone. "There is a wealth of HIV/AIDS information on the Internet," says Mark Fischer, manager of e-health at the **Ontario HIV Treatment Network** ([www.ohtn.on.ca](http://www.ohtn.on.ca)), "but no real place to find Ontario organizations and what they offer."

Until now. This spring, the OHTN launched virtual ASO yellow pages that allow searchers to find services in their area of Ontario. The Web site, [www.ASO411.ca](http://www.ASO411.ca), goes one better than a traditional directory by having visitors search by postal code (so they can find what is closest to them) and by type of service sought or offered.

The listing already contains about 150 organizations that provide services that

include bereavement counselling and volunteer opportunities. While the Web site covers Ontario for now, Fischer says it is a model that can be easily copied in other regions of the country. For more info, contact Greg Mitchell at [gmitchell@ohtn.on.ca](mailto:gmitchell@ohtn.on.ca) or 416.642.6486, ext. 303.

#### QUEBEC Sunday at Simon's

For those with fond childhood memories of *Choose Your Own Adventure*, the book series in which the reader decides what happens next, the Web-based comic strip *Sunday at Simon's* is a new twist.

Simon is a fictional young gay man negotiating the pleasures and perils of life in Montreal's gay village.

Each month, visitors to the *Sunday at Simon's* site follow Simon's adventures to find out how things have worked out since the last episode. Then they vote on what Simon should do next. Just like in real life, Simon doesn't always make the best choice, and sometimes things don't work out.

"*Sunday at Simon's* is part of a project we are launching to promote discussion about a holistic approach to health among gay men," says Doug McColeman, education and prevention director at AIDS Community Care Montreal ([www.accmontreal.org](http://www.accmontreal.org)). "In the comic we want to present a scenario that reflects the lives of gay men and gets them involved." The comic takes a broader, more realistic look at sexual health, including why people put

themselves at risk for HIV and what role HIV-positive people can play in reducing transmission.

McColeman already envisions some surprises for the young character, including one from his friend Pierre-Marc. So, click on [www.directionsmontreal.org](http://www.directionsmontreal.org) and stay tuned!

#### ATLANTIC Stuck Between the Rock and a Hard Place

While Newfoundland's tourism operators may want you to think of the island as a magical getaway from the stress of urban life, Fred Andersen knows that his home province shares many problems with the rest of Canada and its largest cities. "We're just like everybody else," says the injection-drug use project coordinator at the **AIDS Committee of Newfoundland and Labrador** (ACNL). Andersen knows what he's talking about: he recently undertook a study on injection-drug use in St. John's and throughout the province. The results are disturbingly familiar.

Based on a 2005 Health Canada estimate of almost 600 injection drug users (IDUs) in Newfoundland and Labrador, Andersen's study focused less on counting heads and more on identifying what is stopping IDUs from using services that will help them reduce the risk of HIV and hepatitis C. "Users are open to talking and they know about ways to reduce risk," says Andersen, "but it's impossible to [reduce risk] because the services are not there." Persistent lack of awareness and perceptions of stigma among healthcare professionals are other significant barriers. Furthermore, while ACNL runs a needle-exchange program—the only one in St. John's, according to Andersen—standard estimates suggest that such programs serve only 5 percent of the island's users. Andersen is planning education programs targeted to healthcare professionals to better understand the needs of the IDUs in the province. Visit [www.acnl.net](http://www.acnl.net) for more info. +

## Peer Factor

Peer support is an essential ingredient of survival for many PHAs. Here, five HIV-positive peer mentors—who've all been there, done that—talk about life on the job and offer advice to peer counsellor wannabes.

Interviews by **Ronnilyn Pustil**

### CHANTALE PERRON, 40

Coordinator of “jail” project  
Blue Sentry, CAPAHC;  
Liaison Officer,  
Méta d’Ame  
Laval, Quebec  
Diagnosed with HIV  
and HCV in 1992



**ON THE JOB:** As a woman who used injection drugs for 10 years and who lives with HIV and hepatitis C (HCV), I’ve worked for the past several years as a peer counsellor for drug users and people with HIV and/or HCV. Since October 2006 I’ve been in charge of a project called Sentinelle Bleue (Blue Sentry). The principal goal is to make sure that when HIV- and HCV-positive inmates get out of federal jails in Quebec they know where to go for health services. Peer counselling is one facet of this job.

**MAIN MOTIVATION:** In 1998 I decided to look for a job where I could use my personal experience to help others. **My main motivation was to try to help other people avoid the suffering I endured** all the times I tried to quit heroin and to give them the help I wished I had when I was in need. I also want to help prevent others from getting HIV and HCV so they won’t have to face all the difficulties that come with these diseases.

**COMMON ISSUES:** Most of the time my clients talk a lot about HIV or HCV treatment—when it’s not working or when side effects are bad. But there are a lot of other issues they’re dealing with that aren’t as easy to discuss. When I meet a client for a longer session or on several occasions, the most frequent issues that come up are lack of money, difficulty finding a job,

loneliness, the search for a lover and the fear of being rejected.

**GREATEST REWARD:** When the person you’re helping tells you they’re feeling better.

**GREATEST CHALLENGE:** As a peer counsellor I’m not recognized as a professional by certain colleagues, especially those who have a diploma or official title.

**ADDED VALUE:** My own experience allows other people to feel comfortable with me when they come to ask for help. It’s easier for people, especially inmates, to trust and open up to a peer counsellor. There’s less fear of being judged.

**PEER TO PEER:** For anyone who wants to be a peer counsellor, I have two suggestions. First, you have to take care of yourself—fix what needs to be fixed—in order to be able to help others. Second, if you want to be considered a pro, act like one! Work hard, stay informed and be honest and punctual.

### KEN WARD, 50

Crime prevention, Enoch Cree Nation  
Edmonton  
Diagnosed with HIV in 1989

**ON THE JOB:** When I went public with my diagnosis in 1990, I became an HIV-positive Native poster child in the Aboriginal community in Canada. People wanted to know what steps I was taking to stay healthy.

**MAIN MOTIVATION:** I decided to become a peer counsellor based on my own positive experience with peer counsellors after my diagnosis. Their role in my life was life-saving. I didn’t understand the illness itself

and its terminology, and the peers explained it in layman’s terms. It was important for me to understand HIV and how people survive it because I was feeling threatened and afraid. But speaking with these peers provided some sense of comfort and understanding. **I want to encourage people to believe that there is life after diagnosis.**

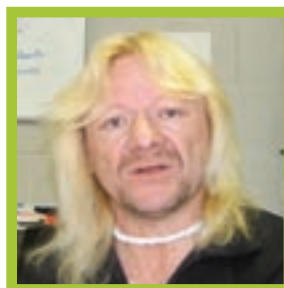
**COMMON ISSUES:** With the population I work with—Aboriginal people coming out of prison and those with addiction problems—the most common issues are homelessness, starting antiretroviral therapy and the doctor-patient relationship.

**GREATEST REWARD:** Helping people create structure in their lives, fulfill their basic needs and be at peace with their diagnoses. Once in a while someone comes around who’s managing well and acknowledges my help with a simple thank you.

**GREATEST CHALLENGE:** Working with extremely high-risk individuals who are dealing with addiction—and all that comes along with that. Getting family support is not easy for positive people and drug users, and stigma and discrimination still exist. Helping people get through those barriers is a big-time challenge.

**ADDED VALUE:** I answer questions about spirituality because that plays an important role in my life. I try to do my best traditionally, which means going to prayers, sweats and other ceremonies. Also, as a former intravenous drug user, I know what it takes to be clean.

**PEER TO PEER:** You have to have a well-balanced way of life. Don’t burn yourself out.



You want to be empathetic and compassionate, but don't own other people's emotions. Set boundaries.

### **RICHARD NERON**, 37

Housing coordinator, AIDS Committee of Newfoundland and Labrador  
St. John's

Diagnosed with HIV in 1988

**ON THE JOB:** I mostly advocate for and work with PHAs who are homeless—women fleeing a violent situation, teenagers kicked out of their houses and those dealing with substance-use issues.

My role is to manage and coordinate shelter and support housing units.

**MAIN MOTIVATION:** Being diagnosed with HIV at 19 was very difficult for me. I felt alone and didn't know what was going to happen to my life. When I got involved in Positive Youth Outreach in Toronto, I learned that I wasn't alone—there were other youth in the same boat. I do volunteer peer counselling because **I want to give back to the community that has helped me so much.**

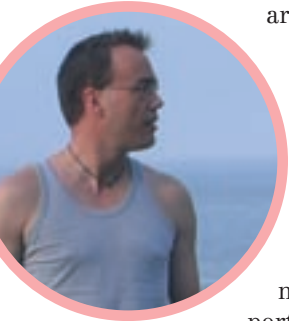
**COMMON ISSUES:** Relationships and sex, mental health, housing, family, employment, school and discrimination.

**GREATEST REWARD:** When I see someone doing well and they think I was a part of it and they thank me. It makes me feel good inside—and when we feel good our immune system gets a little boost.

**GREATEST CHALLENGE:** We can only give our advice—what people do with it is their choice. Also, it's hard not to get emotionally attached to people because you feel for them and know that what they're going through is tough.

**ADDED VALUE:** The client has someone who can relate and who will help in any way. I've been homeless, so I know what they're going through and I feel for them

**PEER TO PEER:** Really listen to the individual and give them suggestions.



Don't tell them they should be doing this or that. It's their choice. Just be there for them.

### **JOAN McLAWRENCE**, 37

Treatment counsellor and peer mentor  
Toronto

Diagnosed with HIV in 2002

**ON THE JOB:** I go to doctor appointments with people, take them clothes shopping, watch their children, go to ASO meetings with them, act as a reference if they're new to Canada. I do active listening with my clients about their issues, concerns, needs and wants—and it's not always about HIV. We also discuss hepatitis C, prevention, financial matters...anything they need to talk about.

**MAIN MOTIVATION:** I used to be a counsellor for young teenage moms. I never thought I'd end up doing this type of work again because it was very stressful, but when I tested positive I came back to it. I like working with my sisters, daughters, nieces and moms—that's what I call them!

**COMMON ISSUES:** Disclosure, stigma and discrimination. It doesn't matter if you're black, white, pink, yellow... these are problems everyone has.

**GREATEST REWARD:** Knowing that I've made a difference in people's lives.

**GREATEST CHALLENGE:** Separating myself from my clients' issues so I don't take them home with me. You can't forget their issues, but you have to remember that you have your own life.

**ADDED VALUE:** My personality and the type of person I am. I get along with everyone. I'm not one to judge.

**PEER TO PEER:** Look within yourself to see if this is what you really want to do. **You have to be able to deal with what's going on in your life before you can deal with other people's lives.** Also, speak to other mentors before you decide.

### **JOHN CAMERON**, 60

"Worn-out old queen with AIDS"

Volunteer  
Richmond, British Columbia  
Diagnosed with AIDS in 1994

**ON THE JOB:** Over the years I've worked with suburbanites, the gay

community, addicts and Natives. Half of my time is involved with boards and communications. The other half is spent hands-on, doing street-level work.

**MAIN MOTIVATION:** After being diagnosed with HIV, I came down with shingles, developed extreme wasting syndrome and was diagnosed terminal. Here in Richmond, there were no services or support for PHAs, but I was adamant that I would not move from the community I'd lived in my entire life. **I promised myself that if I survived I'd do something to change things** around here so I could offer people what I didn't have access to when I was diagnosed. Well, I did survive, and I started an AIDS support group in Richmond. Once a core group of people was established, we created the Heart of Richmond AIDS Society.

#### **COMMON ISSUES:**

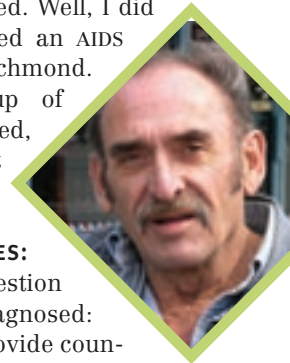
First, there's the question from the newly diagnosed: "What do I do?" I provide counselling and referrals to them. Second question is: "When do I start drugs?" I advise people on when to start treatment and how to sustain it. I try to get across how important it is to adhere to antiretroviral therapy. Third, there's an array of questions on health issues, treatment problems and the daily problems of living with AIDS.

**GREATEST REWARD:** AIDS is now an industry. I find board work and bureaucracy a painful necessity. I retain my sanity through my street-level work because you see direct results. When I walk down the street, people know me—that's the reward. Plus, I've made a lot of friends and had a lot of fun.

**GREATEST CHALLENGE:** Keeping up to date with drug and treatment protocols. The disease hasn't changed, but the treatment has.

**ADDED VALUE:** Food. Whatever I do, I make sure people are fed.

**PEER TO PEER:** Treat people with AIDS as equals, not just as your clients. +





# Growing Old Gracefully

**Recent advances in treatment mean people with HIV are not only living better, they're living longer. Here's how to cope with the new reality.**

**BY LAURETTE LÉVY**

**F**or a person diagnosed with HIV in the 1980s, celebrating a 60th birthday in 2007 is something of a miracle. Before the advent of highly active antiretroviral therapy (HAART) even optimistic estimates of life expectancy didn't exceed 10 years. But times have changed and living well into old age is now a likelihood for people living with HIV. This, of course, has its own ramifications.

Being infected with HIV is no longer a death sentence. For most, it's now a matter of living with a chronic disease, getting older and preparing for retirement—something that for HIV-negative people usually evokes thoughts of a well-earned rest after many years of work. Along with that comes the freedom to choose new activities (such as sports, hobbies, travel) or to spend time with family and friends. In short, it's about embarking on a new stage of life replete with pleasure and leisure. But is it realistic for people with HIV/AIDS (PHAs) to dream about a happy retirement?

## Is it AIDS or Aging?

It would be a mistake to think that everything is rosy for aging PHAs, even if their health is relatively good, at least in terms of HIV infection (undetectable viral load and stable CD4 count). Aging comes with its own health concerns, which tend to pile up more often for PHAs than for the general population: heart issues, high cholesterol, osteoporosis, lung disease, cancer, kidney failure, diabetes and more.

Take Danièle B, now 59. After beginning antiretroviral treatment at age 50 during the throes of menopause, she suffered four bone fractures in six months. The question immediately arose: Were these problems the result of HIV itself, were they drug side effects or were they simply part of the normal aging process? There is no easy answer. However, we do know that PHAs who took the first antivirals in the early days of HAART—with their high toxicity and nasty side effects—are now experiencing earlier onset of many symptoms generally associated with aging.

When your fatigue worsens and your quality of life shrinks, it is normal to wonder if all the medication you've been taking for years has contributed to your liver, kidney and heart problems. While it may be difficult to track precisely the side effects of long-term treatment for HIV/AIDS, one must consider the role played by HIV and anti-HIV drugs given the accelerated aging of the patients who have been taking antivirals since they were first made available.

Dr. Roger LeBlanc, who works in the Immunodeficiency Unit of the Montreal Chest Institute, explains that the body's cells are constantly being bombarded by both HIV and anti-HIV drugs. In response to this assault, the cells reproduce more quickly and attempt to draw on their reserves. However, because these reserves are limited, the system becomes exhausted more quickly and the body begins to age prematurely. So, whether it shows in your skin, joints or organs, the physical aging of the body can be accelerated by 10 years because of HIV.

## Healthy is as Healthy Does

Thankfully, there are possibilities for countering at least some of that acceleration. According to nutritionist Michèle Cossette of the CLSC des Faubourgs, a Montreal health clinic whose clientele consists primarily of PHAs, virtually everyone experiences a metabolic slowdown after age 50 (slower blood circulation, more sluggish pancreatic, liver and intestinal functions). As a result, nutrients aren't absorbed as well and toxins are eliminated less efficiently. How profound these changes are really depends on individual lifestyle.

During the early years of the epidemic, people didn't live long enough for their lifestyle to become a concern—the focus was solely on surviving HIV. We now know that the risks associated with alcohol, tobacco, drugs and poor nutrition have a huge impact on one's health. Just as in the general population, for PHAs the personal realities of aging depend a great deal on lifestyle. In fact, lifestyle plays a more important role in aging PHAs than we thought a few years ago. And the older we get, the more crucial that role becomes.

A person's genetic makeup also has a major impact on his or her health. Even when HIV is well controlled, deaths among PHAs due to cancer, heart attacks and cardiovascular disease continue to occur at higher rates. "People are no longer dying from HIV but from complications related to their lifestyle and genetic background," says LeBlanc.

"Of course, HIV has its effects, as does the medication, but to what degree remains unclear," says nutritionist Cossette. "A person's genetic baggage has to be considered as well, so it is very difficult to ascertain which of these different factors determine outcome."

In one large study conducted in Denmark researchers showed that the incidence of HAART-related cardiovascular disease decreased considerably when other risk factors, such as smoking, alcohol use and obesity, were eliminated.

LeBlanc stresses that physicians must change their attitude toward their patients: "Instead of commiserating with them about their condition, we should urge them to adopt a healthy lifestyle as soon as possible. Obviously, patients have to do their part because they are responsible for staying healthy. Doctors and antiretrovirals cannot do everything. It's no longer enough to rely on your doctor. Patients have to change their lifestyle now." He also recommends that PHAs be monitored like any other patient, with regular blood-pressure tests, weight control measures and blood work to check cholesterol and lipid levels. An infectious diseases specialist is no longer enough—older PHAs need a general practitioner and basic primary care as well. Psychologist Joanne Cyr from the Immunodeficiency Clinic at the Montreal Chest Institute has even proposed to her colleagues that a gerontologist join their team.

## Exercising your Brain

If the physical aging of the body can be accelerated by 10 years because of HIV, the same appears to be true of "cognitive aging," says Cyr, whose ethnically diverse body of clients at the HIV clinic includes men and women aged from 18 to 72. Work needs to be done by PHAs on this front as well. Ed on the West Coast is a good example. He is 65 and, suffering from short-term memory loss, he realized he needed to take on a range of mental activities or exercises to guard against further decline. As a result, he does volunteer counselling work in his Vancouver Island community despite the fatigue that sometimes prevents him from being active.

For Ed and many others like him, staying engaged and informed about new developments and clinical trials can accomplish two things at once. It helps keep the mind limber and at the same time it is important for PHAs needing to stay on top of their condition and medical care, especially those who have experienced treatment failure. It is all a question of finding something that will motivate you: For 62-year-old Lynn, from Nova Scotia, the need for intellectual stimulation and engagement prompted her to join the Community Advisory Committee of the Canadian HIV Trials Network.

Despite good intentions, however, some people understandably do experience a kind of lethargy. It's not easy to remain energetic and committed after years of regular

appointments, blood tests and pill popping, especially when day-to-day issues (concerns about the future, money and loneliness) can play such prominent roles.

## Fiscal Fitness

Turning 65 and facing retirement obviously presents big challenges for everyone, but most Canadians are assured of a decent lifestyle thanks to their pension or savings, and many have the means to realize some of their dreams. However, for those who were forced to stop working at a young age as a result of becoming positive and had to manage without benefit of a private pension, with only meagre disability benefits to rely on, survival and poverty walk hand in hand. Still, a certain outlook can help even with that. Although it's a safe bet that 52-year-old Danièle L. of Quebec is not going on crazy spending sprees on her \$850 monthly income, she insists that she is not poor: "I pay my bills and go out for dinner from time to time with friends."

The two questions regarding aging that Joanne Cyr hears most often from her patients are: "What will happen to me financially?" and "Who will be there to help me?" Indeed, for many PHAs, their financial situation remains complicated and even precarious. The little bit of money people had managed to put aside before getting sick has been spent. Why save money or invest in RRSPs, the thinking used to be, when you were expected to survive only a few years. Many who once were simply not rich have now become downright poor. "At first I could deal with the lack of money because my health was such a huge concern," says Brian, 60 and living in Ontario. "But 18 years later, money has become a bigger issue. With inflation and little or no increase in disability benefits, it's actually worse. You don't get used to it."

What's more, depending on where they live, some people's retirement income may be lower than their

disability benefits. Ed, from British Columbia, saw his monthly income shrink by several hundred dollars as a result of the mandatory switch to retirement benefits from the federal government. Some benefits such as dental may even be cut. And when it comes to drug coverage, people really have to understand the system. "You have to pay attention to pension-related issues because those things are complicated," says Brian. "If you get sick or have emotional and psychological problems, it's easy to let things slide. Then big problems follow."

In situations like this, every dollar counts and access to affordable housing is vital. Lynn, for whom "finances have been a big, big worry," hopes to move to a subsidized residence for seniors soon. As for Brian and Ed, they consider themselves lucky to live in subsidized co-op apartments where their rents account for about 30 percent of their net income—a bargain in today's inflated urban housing market.

"The economic reality affects everything," says Brian. Obviously, having less money means fewer social activities, and even buying clothes is kept to a minimum. "There's a constant pressure. You have less to spend so there's less money for entertainment—eating out, movies, books, a new iPod...it's a different reality. In a way it feels like your potential is gone." The simple life, so to speak, but against your will.

It's paradoxical to think that many of these "poor" people have contributed for years to the survival of countless community, provincial and national AIDS organizations as reliable and indispensable volunteers. These women and men have fought against discrimination, promoted prevention and battled for the improved health of all PHAs—all without any financial recognition for the invaluable time they have contributed to the fight against HIV.

The people who age best have fewer fears and worries.



- CATIE: search “aging” on the CATIE Web site at [www.catie.ca](http://www.catie.ca) or call **1.800.263.1638** to speak to a Treatment Information Educator
- CONNECT Canadian HIV/AIDS Information Gateway: [www.hivinfovoh.ca](http://www.hivinfovoh.ca)
- National Association on HIV Over Fifty (U.S.): [www.hivoverfifty.org](http://www.hivoverfifty.org)
- HIV Wisdom for Older Women (U.S.): [www.hivwisdom.org](http://www.hivwisdom.org)
- The Body (U.S.): search “aging” on [www.thebody.com](http://www.thebody.com)

## A Place for Passion

It's inspiring that despite these kinds of setbacks PHAS still strive successfully for rewarding, meaningful daily lives. As Ed puts it, “My world is small, but there is passion for life in it.” And Lynn says of her hip replacement last year: “It rejuvenated me. My quality of life has significantly improved since. I am moving on.”

Local community groups help make poverty more manageable, offering initiatives that allow PHAS to participate in society and enjoy a better quality of life, such as reduced-cost food buyers clubs, free vitamin programs and complimentary show tickets.

And other tactics can help, too. Many PHAS have attended workshops on “how to stretch your dollar” that have helped them manage their budget. However, a healthy diet rich in fruits, vegetables and friendly fats is getting more and more expensive, and discount stores and food banks seldom offer these products. As a result, coupon clipping and hunting for specials eat up a lot of grocery shopping time when you live below the poverty line.

The need for retirement planning workshops is great nowadays, especially in light of estimates that put one Canadian PHA in five in the over-50 crowd 10 years from now. Ed regrets never having had access to this kind of training. Brian, on the other hand, recently attended a forum sponsored by the AIDS Committee of Toronto dealing with aging with HIV, including financial matters. “The information was very good,” he says. “They covered the specific issues surrounding old-age benefits. If you do get sick, it could be tricky, so you must be on top of these things.” It's this kind of constant worry that has prompted Ed, who retired recently, to consider getting a low-stress part-time job to beef up his meagre pension.

## The Fear Factor

Fear of poverty and fear of being alone go hand in hand. For some, having no partner is a huge source of sadness. Danièle L. would love to rebuild her life with a partner; Brian laments the lack of sharing daily communication; and Danièle B. finds her solitude weighs heavily. “These emotions are shared by everyone who ages,” explains Joanne Cyr. “But they are more difficult to manage for PHAS because they didn't expect to get older and now it's happening sooner than expected.” Many have made peace with their sexual inactivity—due not only to a lack of desire but also to drug side effects that affect sexual performance—and channel their passion into different life pleasures, both big and small, like becoming a grandparent or attending a concert.

For some, solitude and isolation are the consequences of the devastating effects of lipodystrophy. Danièle B. sees only her colleagues and family: “I can't let anyone see me anymore.” Others no longer want to go out: “I'm afraid of the day when it will show on my face,” says one interviewee privately. The effects of lipodystrophy, including facial wasting and fat redistribution, all aggravate aging and generate fears of becoming less desirable and of being rejected.

No wonder the Quebec advocacy group Lipo-Action has called for the reimbursement of liposuction treatments and cosmetic injections. It's not a matter of vanity, but merely a quest for dignity, renewed self-esteem and an end to the endless questions about the cause of the weight loss that's as visible as the nose on your face.

“Getting older is already a challenge in our culture, and to see HIV playing a major role in it distresses people even more,” says Cyr. Especially in a society where facilities specific to PHAS with diminished autonomy are scarce. Brian, who lives in Toronto, knows that being in a big city is an advantage. He says he is not worried because “if one day I become dependent, I can call Casey House. Services are good in a big city. I have had the same doctors for many years and I can talk with them. I feel secure.” That is unfortunately not the case for all PHAS. The existing care infrastructure will have to accommodate the complex needs of aging PHAS, and new rural facilities need to be created so that PHAS in rural areas can also have access to living environments where they can receive the kind of care they require.

As a psychologist, Cyr has observed that the people who age best have fewer fears and worries and adapt more easily. They are also less isolated, continue to have life goals and are actively involved with other people. “Part of my job,” she says, “is to convince people that the decisions they make about lifestyle and health will have an impact on how well they are aging and how they adapt over time.”

The experts have a lot of advice and common sense to offer. Everyone—positive or otherwise—needs to adopt the same prevention strategies as they age, but for PHAS, these strategies are vital: manage your stress, exercise your grey matter, eat healthily and take appropriate supplements, seek strong social support, quit smoking, avoid excessive use of drugs and alcohol and, above all, learn to accept your new limitations.

Brian has an attitude any aging person would do well to adopt. After recent bypass surgery, he says, “I've got a new lease on life. I have learned to live with my health issues on a daily basis. You continue to learn—you have to. Everybody goes through it. You need a good sense of humour. You've got to have a good laugh with good friends. We are still pioneers that way.” +

Laurette Lévy is a member of the CATIE board of directors living in Montreal.



# The Truth *about* Youth

With HIV infection rates among young people on the rise it's clear that we've all got to do a better job of reaching out. But how? We asked the experts—positive youth—what needs to change.

BY COLLEEN PATTERSON

**Young people under 25 make up half of all new HIV infections but are often excluded or ignored as key players in the fight against HIV and AIDS.**

—Toronto YouthForce Advocacy Task Force  
Final Narrative Report, September 2006

**A**mong the loudest messages delivered at the XVI International AIDS Conference held in Toronto last August was this stark reality. And with no sign that this trend will improve, the need for leadership by and for young people with HIV is more urgent than ever. The barriers, unfortunately, are considerable.

Lynn Thompson is an Aboriginal woman in Winnipeg, Manitoba, who has been living with HIV for five years. An AIDS advocate for women, Thompson also does outreach with positive youth—at least she tries to. “Here, the youth are just plain afraid of coming out,” she says. “I’ve actually never met a youth here who is willing to come out.”

There are many reasons that prevent young people with HIV from feeling safe enough to seek support. Among them, stigma, discrimination and fear. Accessing services can also be very difficult for a youth. In fact, Thompson says, “As

advocates and service providers, we have to find the youth because often they are not coming in until they are really sick and very bitter.”

## A Matter of Survival

For many marginalized positive youth, life is simply about surviving. The harsh reality is that many are struggling with issues such as addiction, abuse (sexual, physical, emotional) and lack of housing or a safe place to live, wondering where and how they are going to get their next meal. They have little room to be concerned with things like adherence, nutrition and changing behaviours.

Thompson knows the challenges too well: “There is housing for people who are on disability and when you disclose your health status you’re told it won’t affect your application. But I’ve been homeless for four months in Winnipeg. And I’m 39. I can’t imagine how a 20 year old would even find housing if he or she has to disclose health status. If this were happening to me when I was 20 years old, I certainly wouldn’t have wanted to come out.”

Kecia Larkin, an Aboriginal woman living with HIV in Victoria, British Columbia, is concerned because the city offers no support for her family members, who are affected by her status. “I can’t take my kids to any AIDS service organization because there is no support for them,” she



[www.livepositive.ca](http://www.livepositive.ca)

- Offers a wide range of material geared to youth, including: The Basics, Positive Life, a Library, Message Board, Art Gallery, Fun Stuff (interactive games), Positive Heroes and a Poetry Corner.
- Developed through a partnership between Positive Youth Outreach (PYO), The Hospital for Sick Children Divisions of Adolescent Medicine & Infectious Disease in Toronto, CATIE and TeenNet at the University of Toronto in collaboration with youth and youth-serving agencies across Canada.

says. “My daughter is 14 and there is no place for her to go for support, no place for her to go to have a community.”

HIV-positive youth have to deal with many complex issues concerning the disease that are unique to people of their age group. Among the most challenging is finding programs and support systems geared to their needs and attitudes. Until society and, in particular, AIDS support systems realize this and act accordingly, there is little anyone can do to make a real difference.

## That Big First Step

Danielle Layman-Pleet, 30, former executive director of Voices of Positive Women in Toronto and HIV-positive for six years, sees the need for more and better youth-specific services. “If and when a young person steps through the doors of an AIDS service organization (ASO), it is a really big step,” she says. “If they’re not made to feel they are being served and supported, they’re not going to come back. And that is often what happens, especially with marginalized youth. If you’re pushed away, chances are it’s going to take a long time before you come back...or you don’t come back at all” (see “The Keys to Serving Youth,” page 15).

All too often this is the case for youth. They come in seeking help and advice, and they want it from someone their age, who shares similar experiences, with whom they can connect

and learn from. Youth who are positive have had less opportunity to experience life than their adult counterparts and are still figuring out who they are and what they want to do when they grow up. Often they haven’t had the chance to establish themselves in their jobs or career of choice. Some may not have finished school. In addition, youth more than adults are much more likely to be defined by their HIV status.

Still, while most everyone would agree that there is a pressing need for more programs created *by* young people with HIV *for* young people with HIV—with on-site mentors to help guide them through the bewildering experience of being positive and young—the remedy is not at all straightforward. Lia DePauw, 32, a specialist in youth development and health promotion in Toronto, knows this from experience. “Organizations and services run by both adults and young people often recruit youth staff and volunteers who come from privileged backgrounds,” she says, “perhaps because resources are stretched and they want youth who have ‘skills.’” These “privileged” youth usually tend to be university-educated and very interested in HIV but they may not be personally affected. Angel Parks, 30, agrees it’s a problem. “You want to feel you are dealing with someone like you, who understands you.” Diagnosed four years ago, Angel is both a client and a volunteer at Positive Youth Outreach in Toronto. “ASOs need to observe GIPA [greater involvement of PHAs],” she says, “to create a place of diversity and acceptance.”

## The Future is Now

Layman-Pleet sees another issue: “It is vital in the HIV movement not only that there are youth in leadership roles but that they are mentored, because they are the future of the movement.” When a young person is brought into a youth organization or ASO (whether they are HIV-positive or negative), there needs to be a support structure in place specific to his or her needs. “It is important when you put youth in various positions within an organization that you prepare them for that role,” says Marco Gomes, a 27-year-old Torontonion who was diagnosed with HIV in 2004 and is a strong advocate for HIV-positive youth. “For example, if you are going to put a youth on a board, that youth has to have a mentor. All boards have specific mandates; a youth may have a lot of ideas but perhaps they are not within the mandate of that board. Having a mentor to help the youth understand and gain tools will make their work much more effective.”

Sonika Lal, 28, who has worked in HIV/AIDS and in sexual and reproductive health and rights, agrees. “Being a young person in the field, your ideas and thoughts may be considered fresh and innovative or they may not be considered at all,” she adds. “I think there is sometimes the mentality that young adults are ‘tomorrow’s leaders’ rather than already being leaders who can engage and participate in decision-making roles. The unique life experiences of young people are vital resources.” She also

acknowledges that young people have a lot to learn from their adult colleagues. “I was lucky enough to have great mentors who I not only learned from but who challenged me and gave me great advice.”

Having mentors and structures sensitive to the particular vulnerabilities of youth not only increases the likelihood of success for any young person accessing services or working within an organization, it can also protect them from, for instance, inappropriate sexual comments and advances (a surprisingly common complaint from many in this situation). It is all too easy for the power relationship that can exist between adults and vulnerable young people to result in resentment, alienation and even deliberate exploitation. When an older person abuses a position of power and privilege, a youth will be left feeling uncomfortable, violated or even more isolated than before he or she sought support. Often this type of inappropriate behaviour starts out subtle and escalates into more obvious and overt forms of harassment. Often youth do not realize they are being treated inappropriately until it has gone too far. Organizations serving youth need to ensure that essential safeguards, policies and structures are in place so that effective support and mentorship can take place.

*“I was exploited so social workers and others could learn ‘how to work with youth.’”*

## Token Gestures

There are other challenges. Alex McClelland, 28, who may be the most prominent positive youth activist in the country, has run into his own set of hurdles. “[When I tested positive] all I wanted was someone my age, a peer with the same experiences to share, to help me understand how to live through the trauma of the whole experience,” he says. “Instead, I spent a lot of time feeling uncomfortable and out of place. I had quite a few bad experiences.”

In retrospect, McClelland realizes that he was asked to take on more than he was ready for at the time. “All I wanted was support, but instead I was thrust into a leadership role,” he says. “I was often asked to take part in workshops and presentations as a speaker. I think I was way too young and vulnerable to be doing it. I was exploited so social workers and others could learn ‘how to work with youth.’”

The problem is that the very organizations that are trying to help often unwittingly compound the problem. “Organizations often resort to tokenism without realizing they are doing it,” says Layman-Pleet. “This happens when structures are not set up to equip the young person with the tools they need.” McClelland,



diagnosed with HIV almost 10 years ago when he was only 19, agrees: “I was often exploited to make other people’s work look like they had included a ‘youth voice.’”

A turning point came when McClelland realized he needed to take charge. “Eventually I learned how to turn the tables and empower myself while doing education and advocacy work in the community.” He became involved with a group of young people in Positive Youth Outreach and they started running their own workshops. “We recognized there was a gap in services so we researched the needs of youth living with HIV in Toronto,” he says. “We were empowering ourselves with up-to-date information about what our peers needed and taking control. Funders and community started to listen and realized that youth knew best how to meet their own needs.”

At the end of the day, McClelland says he does not feel disappointed about how he was treated. “Those experiences do not bring me down. I learned from them, and I hope the adults involved learned from them as well,” he says. “I was a person who ended up filling a void and being a voice where there wasn’t one before. Ultimately, my work has empowered me, and I ended up connecting with many other positive youth around the country. Now there are more of us positive youth becoming involved and that makes me proud.”

For Marco Gomes, the key to successful HIV services for youth comes down to empowerment and respect. “We need to focus our attention on youth and let them know that having fun is not a bad thing, but there are ways they can protect themselves and their partners from HIV,” he says. “They should have the liberty to get a condom without being questioned and we should provide information that will educate them. Youth need to get involved and be given proper training and opportunities, because young people are the best educators for themselves.”

Gomes feels strongly that positive youth need and deserve a voice—and that they can do it on their terms. “To youth I say, try to learn as much as possible and don’t accept it when people say you are not qualified to be a part of this or that. Being a youth leader doesn’t mean you have to be a poster child for HIV. It may mean standing up against stigma and discrimination and saying, ‘I’m a youth and I don’t think that’s right.’ That, too, is being a leader—bringing about change by talking to one person at a time. You can be a small leader or a big leader.” +

*“Young people are the best educators for themselves.”*

Colleen Patterson, until very recently the director of communications for the Red Road HIV/AIDS Network in Vancouver, was Chief Youth Rapporteur at AIDS 2006.



## The Keys to Serving Youth

CATIE’s youth liaison Sugandhi Wickremarachchi spoke to Jason Asselin, coordinator of Positive Youth Outreach (PYO), a peer-driven program with the AIDS Committee of Toronto (ACT), about what agencies need to do to best serve young PHAS.

- Get youth input into programming meant for them.
- Understand that identity issues are very important to young people.
- Tailor your offerings to your audience: one youth program cannot serve all youth.
- Create a safe space where confidentiality and trust are guaranteed.
- Offer psycho-social support and education to foster self-confidence and independence.
- Understand the specific developmental issues associated with infant and childhood seropositivity and know that perinatally infected youth confront different issues than those recently infected.
- Ensure a non-judgmental, supportive environment.
- Consider the range of literacy levels of youth.
- Be helpful in negotiating both health and social service systems.
- Let them be themselves; consider creating specific places and times during which only youth will be present.





Cultivating *C*ompassion

ILLUSTRATIONS: © IAN PHILLIPS/WWW.I2ART.COM



Operating in a legal no-man's-land and facing criminal action at any time, dedicated activists at compassion clubs across Canada are working to make medicinal marijuana available to any PHA who needs it.

**Derek Thaczuk** explores how they work and why they are so important.

*On*

April 23, 2004, at the New Brunswick Cannabis Café in Saint John, owner Lynn Wood phoned a new applicant's doctor's office as usual to check that all was above board—unaware that she was actually speaking to a detective. The café, a compassion centre that provided medical marijuana to people with conditions including HIV/AIDS, was short-staffed that day. An inexperienced employee missed the step that usually came next—verifying the doctor's name with the College of Physicians and Surgeons—and Wood went ahead with supplying a gram of marijuana to the applicant. Shortly afterwards, more than a dozen police officers burst through the door, and Wood was on her way to jail for selling marijuana to an undercover police officer. Six months pregnant, Wood received a one-year sentence, with only enough time off to deliver her baby outside the jail.

The New Brunswick Cannabis Café (NBCC) isn't the only compassion centre in Canada to have found itself busted. In August 2002, six plainclothes police officers knocked down the door of the Toronto Compassion Centre (TCC). Despite prior verbal agreements between police and the centre that any problems would be resolved peacefully, programs coordinator Mary Jane Morgan found herself with a gun pointed at her

head. “Even the fish in our aquarium were freaked out,” she says.

And recently, in March 2007, London Compassion Society owners Peter Young and Robert Newman were arrested and charged with marijuana cultivation and trafficking. Both spent two days in jail and, at the time of writing, are out on \$25,000 bail awaiting trial, prohibited from having any contact with one another and not allowed in the downtown core of London, Ontario.

There is one precedent Young and Newman can look to for hope. It’s the case of Vancouver Island Compassion Society (VICS) founder and director Philippe Lucas, arrested and charged with drug trafficking and possession in November 2000. More than 20 court appearances later, on July 5, 2002, Lucas received not only an absolute discharge but praise from the court. A report on the case in the September 17, 2002 issue of *The Canadian Medical Association Journal* noted that the judge “lauded Lucas’s motives, transparency and meticulous record-keeping.”



### WHAT ARE COMPASSION CENTRES?

Compassion centres (or compassion clubs)—businesses that exist to sell marijuana to people with medical conditions including HIV/AIDS—are clearly outlaws. They differ dramatically from “garden-variety” dealers in that they grew out of the medical marijuana activist movement and, accordingly, treat marijuana as a medicine—albeit a controversial and often illegal one. Clubs will only sell to people with officially documented medical conditions—such as HIV/AIDS, cancer, glaucoma, hepatitis C, chronic pain and multiple sclerosis. With access to clean, inexpensive, high-quality cannabis in a welcoming, wellness-oriented setting, clients aim for relief from their symptoms—pain, stress and the nausea and loss of appetite often caused by pharmaceutical treatments for their conditions. Some clubs provide relaxed settings for clients to take their medication on the premises.

According to the Canadian AIDS Society, 16 compassion centres are currently operating in Canada (see list, page 22). While not governed by any formal umbrella organization, they form a loose-knit network ascribing to common principles. *Guidelines for the Community-Based Distribution of Medical Cannabis in Canada*, co-authored by Rielle Capler, advocacy and research coordinator at the British Columbia Compassion Club Society, and Philippe Lucas, defines a set of voluntary standards by which most compassion clubs choose to operate.

For instance, cannabis can only be sold to members—people who have applied, provided ID, and whose medical information is confirmed by their physicians. (Patients must provide written permission to their doctors to share

confidential medical information with the clubs.) Members may not resell or share any product they buy, on threat of expulsion. Nearly all clubs also provide advice and guidance on how to use cannabis, avoid unwanted effects and stay within the law—tips that are especially helpful for new users. “Maybe half of our members are people who weren’t hippies,” says the TCC’s Mary Jane Morgan. “They don’t know about marijuana. We get to know them and what’s going to help them best: which strain, how much, how to take it...whatever they need to know.”

Recognizing how rigorous most clubs are in restricting their sales to people with medical conditions, many police

## The knowledge, experience and support of compassion clubs give them a significant edge over the Health Canada program.

departments let them operate under the radar in a sort of unwritten, off-the-record truce, but it is a truce that can give way without warning at any moment.



### CRIME TO TREAT SICKNESS?

While pot will probably never lose its tie-dyed toker Cheech and Chong rep, thousands of people with HIV/AIDS, cancer and other serious illnesses find it an effective way to help manage their symptoms. Many rely on marijuana to settle stomachs sick from HIV, antiretroviral treatments and cancer chemo—and to bring on the famous munchies. Smoked cannabis quells AIDS-related neuropathic pain twice as well as a placebo, according to a study by Dr. Donald Abrams, professor of clinical medicine at University of California, San Francisco (published in *Neurology*, February 2007), and research is investigating other potential benefits.

Today, despite the fact that marijuana is illegal, Health Canada can make exceptions for people with grave and debilitating illnesses. In 1998, however, marijuana was not legal under any circumstance in Canada. Back then, AIDS activist Jim Wakeford and epileptic Terry Parker took to the courts in two landmark cases, defending their right to better their health without fear of arrest. (As Wakeford told *The Positive Side* in 2002, “It’s not a crime to be sick.”) In May 1999, Wakeford was granted the legal right to use marijuana. Furthermore, in July 2000, the court ordered Health Canada to set up a mechanism by which other seriously ill Canadians could do the same. The Marijuana Medical Access Regulations (MMAR) came into force in July 2001: armed with a doctor’s support and the proper paperwork, sick people could now legally grow, possess and use marijuana to treat their illnesses.

But the battle didn’t end there. The MMAR allowed for legal possession but made no provisions for legal supply.



## ACCESSING MEDICAL MARIJUANA

### Things to consider:

Marijuana is illegal. Health Canada can make exceptions for people with “grave and debilitating illnesses.”

Having HIV/AIDS does not, in itself, qualify you for this legal exemption. If you are HIV-positive and suffering from severe pain, nausea, wasting or weight and/or appetite loss, you can apply to Health Canada’s Marihuana Medical Access Division—you will need a doctor’s support as well as medical documentation of your condition. Details and application forms are available on Health Canada’s Web site:

[www.hc.sc.gc.ca/dhp.mps/marihuana/index\\_e.html](http://www.hc.sc.gc.ca/dhp.mps/marihuana/index_e.html)

This site also describes how to gain access to Health Canada’s medical marijuana supply. The government of Canada does not recognize compassion clubs as a legal source.

For more info and a list of Canadian compassion centres, see the Canadian AIDS Society’s *Medical Marihuana: A Guide for PLWHIV/AIDS and their Caregivers*, online at:

[www.cdnaids.ca/web/backgrnd.nsf/pages/cas-gen-0040](http://www.cdnaids.ca/web/backgrnd.nsf/pages/cas-gen-0040)

### Things to look for in a club:

Any place can call itself a compassion club. The standards and guidelines discussed in this article are voluntary—not everyone adheres to them. Use your own judgment when using services.

Questions to ask:

- How secure is my confidential information—medical and otherwise?
- How is your cannabis grown? Is it safe for sick people to use, free of pesticides, moulds and toxins?
- Can you offer advice for new users?
- Can you offer alternatives to smoking (vaporizers, ingestibles)?

Above all, never forget that compassion centres are still illegal—even if it’s legal for you to use medical marijuana, it’s not legal for anyone but Health Canada to sell it to you.

After further court hearings by Wakeford and others, the Ontario Superior Court ruled in January 2003 that legal permission without a legal supply amounted to no permission at all. Health Canada—which had already contracted Prairie Plant Systems (PPS) of Flin Flon, Manitoba, to grow marijuana for research purposes in December 2000—now reluctantly began distributing the PPS crop. As a result of that court decision, legal MMAR holders can now apply to Health Canada to purchase dried marijuana at \$5 a gram (and/or seeds to grow their own), delivered directly to them by courier.

Health Canada’s most recent statistics (April 2007) reveal that 1,742 Canadians are currently legally entitled to possess marijuana under the MMAR and, of those, 351 are accessing the government’s legal supply. A further 444 have ordered Health Canada-supplied seeds, of whom 170 are receiving a temporary supply of cannabis until their seeds yield a usable crop. Yet far more Canadians—close to 10,000—are estimated to be registered with compassion clubs.

Why do they brave such thin legal ice? Arguments have raged over the quality of the PPS product. Recipients of PPS pot have criticized it for low strength and purported contamination by toxic metals. (Health Canada’s own data shows a biologically pure product with THC—the active ingredient in marijuana—content near 12 percent and metal and other toxin levels well within Canadian safety standards.) PPS president Brent Zettl has stood by his product, rejecting criticisms he says are not backed up by evidence. Yet in 2006, through the Access to Information Act, VICS founder and director Philippe Lucas obtained copies of more than 2,000 complaints received by Health Canada about the quality of its program and product—more than one complaint for every day of operation.

As well, the knowledge, experience and support of compassion clubs give them a significant edge over the Health Canada program, which is set up only to provide and deliver the marijuana. Although PHA activist and retired physician Greg Robinson acknowledges that he feels much more secure having the government’s legal entitlement to use marijuana, he says: “The government supply is not a good solution. The compassion clubs offer me advice, information and experience—an understanding of how to use this substance for my benefit. Health Canada has demonstrated that they simply can’t provide that kind of experience and knowledge.”



### THE FIRST SEEDS SPROUT IN B.C.

Canada’s first compassion clubs were established before any such thing as a legal government source existed. The very first such centre, the British Columbia Compassion Club Society (BCCCS), was founded by medical cannabis user and activist Hilary Black in 1997. As BCCCS’s Rielle Capler tells it: “Hilary was working at a hemp store downtown, seeing more and more older people and sick people

asking where they could get cannabis to help with various illnesses. Cooperatives were just opening up then in other countries. Hilary spent some time in Holland and California studying their operations, then got together with some people up here and started BCCCS.”

Anyone with a grow lamp and a mind to do so can sell pot. So why go that extra mile? Why do compassion club owners, staff and volunteers paint bull’s eyes on their foreheads—risking arrest by setting up such visible, vulnerable operations?

Pete Young and Rob Newman co-founded the London Compassion Society (LCS) in 1998 in Ontario with a donated pound of marijuana “out of an old army safe in the back of a head shop.” Newman, HIV-positive himself, says, “I’m a huge AIDS advocate. I like to do things that push the envelope, to get involved in things that pose questions and challenge things. I think the whole AIDS community is known for that, for pushing tough issues like this one.”

When Philippe Lucas tested positive for hepatitis C in 1995, he started doing research to see if cannabis might be harmful to his liver. All the published studies he found showed nothing of the kind. Instead he found out that it could potentially help the symptoms he was starting to experience (nausea, loss of appetite, pain from liver swelling). “Our drug policies were not in keeping with the science or evidence,” says Lucas. “As a 25-year-old white male I had no trouble finding cannabis in the city of Victoria. But I did have trouble finding a *consistent* supply—something effective every time. So I started growing my own and learning about it.” Four years later, in 1999, Lucas met with BCCCS director Hilary Black and went home determined to start a similar organization. He opened the Vancouver Island Compassion Society from a storefront in October that year.

On the legalities of operation, Lucas says: “Compassion clubs take the most vulnerable victims—medical cannabis users—off the front line of the drug war. I don’t think there’s any jurisdiction in Canada where the police actually want to arrest people with HIV or cancer [who use cannabis for medical reasons]. By providing this service, we’ve served not only our membership but also the police, by helping them to distinguish medical from recreational users.”

No doubt medical users would rather find effective treatments that are legally available. For that matter, why not stick to the perfectly legal synthetic cannabinoids, nabilone (Cesamet) and dronabinol (Marinol)? Robinson explains why many people avoid them: “If I could get the right effects from a pill, I’d use it. But Marinol and Cesamet just wipe me out.”



### HERE DOES THE MONEY GO?

Best intentions there may be, but cannabis still means business. Even a smaller centre like the LCS has 200 clients. Some 2,000 are registered with TCC; double that with

BCCCS. At roughly \$10 a gram, couldn’t that add up to a tidy profit?

Not at the LCS, says Newman. Interviewed before his bust early this spring, he put it plainly: “I don’t drive a Cadillac. All our employees rent, nobody owns a home. We just turn all the money back over to the club because that’s what it’s all about. We have actual employees now, with salaries to pay, but even that’s bare minimum. [Founder] Pete Young doesn’t take a salary at all.”

At BCCCS, a registered non-profit agency (which has recently become a member of the Canadian AIDS Society), Rielle Capler says, “We are as accountable as any other non-profit agency. We do everything we possibly can to enhance our transparency and accountability—we want to show the vision of what this could be if we operated in a



## MEDICAL CANNABIS PATIENTS BILL OF RIGHTS

**Written by Philippe Lucas of the Vancouver Island Compassion Society, this Medical Cannabis Patients Bill of Rights was designed to outline the basic rights of medical cannabis users, and to protect them from stigma, arrest and prosecution.**

- I am not a criminal; I am a person living with a medical condition and use cannabis to alleviate my suffering; I am capable of making fundamental decisions about my health.
- I have the right to live free of unnecessary suffering, social stigma and interference from the state, and should not have to choose between my personal liberty and my health.
- I have the right to produce my own medicine if I am willing and able to do so, or to access it from a safe source without fear of arrest and persecution.
- It is the federal government’s moral, legal and constitutional obligation to defend these basic and inalienable human rights, and to ensure that no organization or individual unduly interferes with them.

<http://compassionatecanadians.com/billrights.php>

legal environment.” Does BCCCS set the industry gold standard? That’s what it has been striving for. Two years ago, the centre applied for and received a grant from a large financial institution. “We went through a really intense process,” says Capler. “Their ethics committee looked under every rock and found that our ethical standards equalled or exceeded their requirements.”

## MORE THAN JUST MARIJUANA

Whether they operate under a for-profit or non-profit model, many operations channel funds from sales back into other projects that support their clients’ health and the future of the medical marijuana movement. BCCCS operates a wellness centre, as did the LCS before it ceased operations. The BCCCS model has always been a holistic healthcare centre, says Capler. “People come to us because they’re interested in natural and holistic health. They’re finding there’s more to healthcare than what the pharmaceutical industry has to offer. But many holistic services are hard to access because their costs are not covered.” The BCCCS uses money from sales to subsidize complementary and alternative services offered by herbalists, nutritionists, Reiki therapists, doctors of Chinese medicine and craniosacral therapists. “There are wait lists, but once clients get to see a practitioner they can see them for as long as they need to. At any one time about 300 people are using the services.”

**“People come to us because they’re interested in natural and holistic health. They’re finding there’s more to healthcare than what the pharmaceutical industry has to offer.”**

Before the LCS shut down, three rooms were rented out to therapists. While therapists weren’t LCS employees, they had to be completely knowledgeable about what LCS did. The therapists ran their own registered massage therapy, hot-stone therapy or aromatherapy services and gave LCS clients a 50 percent discount.

## REEFER RESEARCH

At the Vancouver Island Compassion Society, the emphasis is on research—an area still moving at a glacial pace through “official” research channels. “Cannabis has been well researched internationally,” says Lucas, “but Health Canada and the Canadian Medical Association keep saying ‘we don’t know enough about this, there’s no research.’ I realized that with all our members we’d be great research centres. It made eminent sense in terms of recruiting and gathering info quickly, efficiently and at low cost.” In a prime example of community-based research,

Lucas took the initiative, teaming up with academic partners from the University of Victoria and the University of British Columbia (UBC) to develop research protocols and ensure the project’s scientific rigour and credibility. In January 2006, the respected *Journal of Complementary Therapies in Clinical Practice* published the first fruits of their labour, a paper entitled “Survey of Cannabis Use Among Childbearing Women,” jointly authored by Lucas, Capler, Rachel Westfall from the University of Victoria, and UBC’s Patricia Janssen.

Several other studies are also in the works, in collaboration with academic researchers and intended for publication in respected journals: “If it’s not peer-reviewed and published it’s simply not going to carry much weight. That means a longer, more cumbersome and more expensive research process, but if we’re serious about showing ourselves as credible research providers, we have little choice but to jump through those hoops,” says Lucas. “I love the research we’re doing.” So do others, apparently: in April, the University of Victoria honoured Lucas for “remarkable contributions to the university and the greater community.”

## HELPING THE FEDS

Many of the activists behind compassion centres are working to improve the very federal system they often find themselves pitted against. “We feel it’s important,” says Lucas, “even as we’re working outside the system, to try to fix the federal medical marijuana program.” A research study he is working on with McMaster University will collect user feedback about the Health Canada program—something, Lucas points

out, the federal program itself has never done.

It’s not as if compassion clubs’ business base is threatened by Health Canada’s program—today, the clubs serve some 10,000 critically and chronically ill Canadians. What activists want first and foremost is to compassionately provide people in need with high-quality medical marijuana and knowledgeable advice. Pushing for change comes with the territory. Those 10,000 Canadians, after all, would be best served if the federal system was improved *and* clubs were granted legal status. Meanwhile, the last word may belong to Lucas: “We’re doing more research than Health Canada, producing a better and safer cannabis supply and we’re doing it all at no cost to the Canadian taxpayer.” +

Derek Thaczuk has worked in the HIV community for many years, providing support services and accessible treatment information. He has worked as a treatment educator with CATIE as well as a freelance writer and editor.





# COMPASSION CLUBS ACROSS CANADA

## **Treating Yourself.com Inc.**

Canada-wide  
E-mail: weedmaster@treatingyourself.com  
Web site: www.treatingyourself.com

## **Cannabis Buyers' Club of Canada**

Victoria and Coombs, British Columbia  
Halifax, Nova Scotia  
Tel: (250) 381.4220 on the West Coast  
(902) 497.3941 on the East Coast  
E-mail: normlms@hotmail.com

## **The Vancouver Island Compassion Society**

Victoria, British Columbia  
Tel: (250) 381.8427  
E-mail: info@thevics.com  
Web site: www.thevics.com

## **Island Harvest-BC Certified Organic Medical Cannabis**

Vancouver Island, British Columbia  
Tel: (250) 748.8614  
E-mail: info@medicalmarihuana.ca  
Web Site: www.islandharvest.ca

## **The Mid-Island Compassion Club**

Vancouver Island, British Columbia  
Tel: (250) 954.0363  
E-Mail: MidIslandCompassionClub@Shaw.ca  
Web site: www.Members.Shaw.ca/MidIslandCompassionClub

## **British Columbia Compassion Club Society**

Vancouver, British Columbia  
Tel: (604) 875.0448  
E-mail: info@thecompassionclub.org  
Web site: www.thecompassionclub.org

## **remarcable foods**

Vancouver, British Columbia  
Tel: (604) 721.7461  
E-mail: info@remarcable.ca  
Web site: [http://increationwetrust.org/  
Remarcable%20backup/remarcable/THC.html](http://increationwetrust.org/Remarcable%20backup/remarcable/THC.html)

## **Nelson Cannabis Compassion Club**

Nelson, British Columbia  
Tel: (250) 354.4206  
E-mail: nelsoncompassion@yahoo.ca

## **Mobile Access Compassionate Resources Organization Society (M.A.C.R.O.S.)**

Edmonton, Alberta  
Tel: (780) 457.6824  
E-mail: admin@macros.ca  
Web site: www.macros.ca

## **London Compassion Society**

London, Ontario  
Tel: (519) 850.5221  
E-mail: info@londoncompassionsociety.com  
Web site: www.londoncompassionsociety.com

## **Cannabis As Living Medicine (C.A.L.M.)**

Toronto, Ontario  
Tel: (416) 367.3459  
E-mail: info@cannabisclub.ca  
Web site: www.cannabisclub.ca

## **Cannabis Common Inc.**

Toronto, Ontario  
Tel: (416) 400.3134  
E-mail: cannabiscommon@sympatico.ca  
Web site: www.toronto420.com/cc

## **Hemp Users Medical Access Network**

Toronto, Ontario  
Tel: (416) 253.1021  
E-mail: info@humanhemphealth.ca  
Web site: www.humanhemphealth.ca

## **Toronto Compassion Centre**

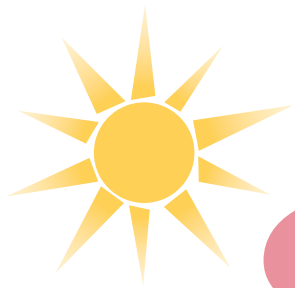
Toronto, Ontario  
Tel: (416) 668.6337  
E-mail: postmaster@torontocompassioncentre.org  
Web site: www.tccentre.org

## **Montreal Cannabis Club/ Marijuana Home Delivery**

Montreal, Quebec  
Tel: (514) 521.8764  
E-mail: contact@marijuanahomedelivery.ca  
Web site: www.marijuanahomedelivery.ca

## **Montreal Compassion Club**

Montreal, Quebec  
Tel: (514) 532.9961  
E-mail: info@clubcompassion.net  
Web site: www.clubcompassion.net



# Staying on the Road to Health



**More and more studies show that the route to optimal health for anyone on meds is adherence: you've got to stick to your demanding drug regimen. We ask the experts—doctors, researchers and PHAs—how to stay on track.**

**BY DAVID MCLAY**

## W

hen it is time to start a regimen of anti-HIV medications, the most obvious need is finding a drug combination that will bring your viral load down, ideally to an undetectable level. But there's a second consideration that's just as important: being fully committed to taking the drugs. The act of taking your meds as prescribed and directed is called "adherence," and as we gain more experience with these drugs, experts and people with HIV/AIDS (PHAs) are gaining new understanding of how it all works.

Medical experts preach adherence, insisting that anti-HIV meds—generally known as HAART (highly active antiretroviral therapy)—always need to be taken at exactly the right

time and in exactly the right way. If not, there's the spectre of a resistant virus, which can lead to the need to switch meds, which ultimately limits treatment options.

Studies have revealed that PHAs must take their pills correctly 95 percent of the time for drug levels to remain high enough in the blood to block the virus from replicating. (That's one missed dose per month of a once-a-day regimen, or three missed doses of a twice-a-day regimen, though research is showing that some drugs might be more "forgiving" than others.) If adherence drops even a little bit, say, down to 85 percent (four missed once-a-day doses per month, or nine missed twice-a-day doses), drug levels enter the danger zone, where the virus can replicate and become resistant. And taking a dose late can have the same effect, meaning that not only is it important to take your medication, it is also important to take it at the right time.

The push for adherence is based on pharmacokinetics (a fancy word for how a drug behaves in our bodies) and our lab-based understanding that the virus is only held in check under certain very stringent conditions. One serious challenge with this medical view of adherence is that it doesn't take into account the fact that PHAs will be popping pills every day for years and years. Take Bill, for instance: he's 55 and has been HIV-positive for about 25 years. He started meds in the mid-1990s. That means that by now he has taken at least 40,000 pills. With recent advances, experts predict that, like Bill, many PHAs on treatment can live out their natural lifespans, which is obviously a great step forward. For Bill, who has many years ahead of him, it means thousands of more pills. The challenge for Bill and for every PHA on anti-HIV therapy is to find the stamina to stay adherent.

### *Pill-popping prep*

Adherence seems like one of those things that would take the most effort once you begin treatment. But experts are beginning to realize that there is a lot of work to be done before the first pill is popped. Getting ready and committing to the therapy before starting it can help people adhere in the long run.

This idea is called treatment preparedness. On a practical level, this commitment can mean answering yes to questions such as "Can you adjust your schedule to fit pill-taking in at

## Getting ready and committing to the therapy before starting it can help people adhere in the long run.

regular intervals, regardless of where you are?" and "Can you ride out the side effects that will invariably occur during the first couple of months?" But sometimes, it's the questions behind these questions that can play a bigger role in staying committed to HAART. What does it mean to start HAART? What fears and expectations are raised by the idea of starting HAART?

Bill lived through his own version of becoming prepared for treatment. When AZT first became available in the mid-1980s, he refused to start because he wasn't ready to take pills for the rest of his life. But he made a deal with his doctor—he promised to start treatment if his CD4+ count fell below the critical value of 200. About 10 years later, the count reached 175, and Bill knew it was time to start meds. His doctor and healthcare team were supportive, telling him not to start until he was completely ready. Bill took about a week to prepare; during that time, he laid out some of his fears and concerns in a letter to himself. He worried about how the meds would affect his body, especially his liver. And he wondered how he would cope with drug side effects like nausea and chronic diarrhea.

Declining CD4+ counts and high viral loads often trigger talk about starting meds. But not all PHAs have the time that Bill had to prepare. They can feel forced to start meds before they are truly ready. As a result, some end up not adhering because they're not committed to the treatment plan. A 2006 U.S. study followed more than 3,400 PHAs who were starting HAART to see how many stopped taking meds and why. After following up one year later, researchers found that adherence issues were second only to side effects as the reason given for stopping therapy: about 13 percent of PHAs stopped taking their pills because they couldn't adhere to their regimen.

Accepting the importance of taking meds is not always easy. Anti-HIV meds work in a way that's contrary to how we usually think about taking medicine. With other illnesses, most of the time we get sick and then take pills to get better. In those cases there's some immediate payoff for putting up with the inconvenience of adhering. But HAART is the opposite. People are usually not severely ill when they start (though they sometimes have nagging health problems, such as lingering skin infections), and so there is no obvious benefit to be gained right away. Instead



they are investing in something intangible—a healthy future. So they are paying now for something they won't get until later. That's not an easy sale.

### *Facing the future*

For PHAs who received their HIV diagnosis when they were feeling healthy, starting meds can be the first time that they are facing HIV in a real and concrete way. Gillian Kolla, treatment buddy program coordinator at AIDS Community Care Montreal (ACCM), recounts the story of a client who brought home his first set of meds. He lined up all the pill bottles on the table, and as he sat there looking at his first dose, he said to himself, "This is real." The emotional issues surrounding a diagnosis of a chronic, incurable condition such as HIV can be difficult to face, and adherence may suffer in the meantime. The program that Kolla runs at ACCM pairs people who are starting or switching a HAART regimen with people already on meds. The goal is to offer personal experience and support through the difficult early days.

Another worry for PHAs concerns how meds will affect their social and personal lives. Disclosure of HIV status can become an issue when taking meds, because popping pills is a very obvious sign of sickness. And many people, while sincerely concerned, end up just seeming nosy. Often, PHAs who aren't on meds don't show any sign that they have HIV, and so it is easy to maintain control over who knows and who doesn't. And there is still a lot of stigma around HIV, so it does matter whether or not someone knows. When looking for ways to deal with disclosure, AIDS service organizations and other PHAs on meds are good resources.

Thrown into this mix is the fear of drug side effects, especially the long-term ones. Frequently, some of the more common side effects, such as diarrhea, nausea and headaches, hit hard at the beginning and then subside. But the one that causes more concern is lipodystrophy—the changes in fat metabolism and storage that are estimated to affect 30 to 50 percent of PHAs on meds. Lipodystrophy is sometimes associated with changes in the body shape, especially the loss of fat under the skin (lipoatrophy) that causes the sunken face that many PHAs feel is a dead giveaway of their HIV status. While increased risk of heart disease and diabetes are more medically serious, facial wasting is troubling in another way—it's like



wearing a sandwich board that says: "I have HIV."

Researchers have discovered that lipoatrophy is most commonly associated with certain drugs, in particular, d4T (Zerit) and, to a lesser extent, AZT (Retrovir). These drugs were common in older combinations, but with new drugs available it might be possible to avoid using d4T. This

is something PHAs should take up with their doctor when discussing starting meds. And even if certain problem drugs can't be avoided, PHAs can watch out for early signs of fat change and be ready to take action. Changing a drug in a combination can help slow or stop fat loss, but an early response is crucial because getting the fat back is a slow process, if it happens at all. There are also surgical options, including injections of "fillers."

### *Deciding with doc*

The topic of starting meds is a discussion that may last over several doctor visits. But face-to-face time with your doctor is precious and often there isn't enough of it for a lengthy discussion about all the pros and cons of treatment. Dr. Ahmed Bayoumi, director of the Clinical Epidemiology program at the University of Toronto and a clinician at the HIV clinic in St. Michael's Hospital, is working to develop a decision aid that will help PHAs decide whether it is a good time to start HAART and what their first regimen should be. The computer-based interactive program will help explore in-depth issues that a physician can't cover in a brief visit.

The idea of a decision aid comes from research into people living with cancer, which has found that patients who have used this tool when it comes to treatment options are more likely to be comfortable with their decisions. Bayoumi says it is logical to expect that someone who is more comfortable with the decision to start meds will be more likely to adhere.

While the adherence decision tool is still in development, Bayoumi says that it will take in all the key factors related to making decisions about treatment, including apprehension about both short- and long-term side effects, level of commitment to the idea of taking meds, and concerns around confidentiality. Bayoumi says that his own patients "have to be ready for the commitment of taking pills. I do my best to help them understand why they

*A* client  
brought home  
his first set of meds.  
As he sat there looking  
at his first dose,  
he said to himself,  
"This is real."

should be taking pills. I explain the risks of not starting meds and the risks of starting them. But they decide when it is time.”

So, what if you’re not ready to start treatment? You’ll no doubt run into some opposition from your doctor, especially if your numbers are getting close to the critical values. In your doctor’s calculation, the risk of serious medical complications increases with every drop in CD4+ count. But your doctor may not see the same risk equation you do. Bayoumi offers a professional perspective: “Doctors like to minimize risk. But some patients are more willing to take risks. If you and your doctor have different ideas about starting meds, you should be able to communicate your thought process to your doctor so she can understand where you’re coming from.”

PHAs and doctors can hold very different views of HAART, according to a 2006 survey conducted by the International Association of Physicians in AIDS Care. The survey asked 400 PHAs and 150 HIV doctors in the U.S. about different aspects of HIV treatment. Sometimes PHAs and doctors

Daniel, 30, was diagnosed in April 2006. He started meds soon afterwards due to falling CD4+ counts and an uncontrolled viral load. Currently, he takes unboosted atazanavir (Reyataz), two pills once a day, and Kivexa (abacavir + 3TC), one pill once a day. He takes all three pills just before going to bed at 10 pm.

Atazanavir is often prescribed with another protease inhibitor, ritonavir (Norvir), in a strategy called boosting. Taking a bit of ritonavir increases the levels of atazanavir in the blood, meaning more potency with less drug. But Daniel experienced headaches and nausea, common side effects from ritonavir. And his liver produced increasing levels of bilirubin, which can cause yellowing of the skin. In Daniel’s case, the bilirubin caused his eyes to turn yellow. He couldn’t handle it. After one month, he and his doctor decided to drop the ritonavir and increase the atazanavir. The side effects settled down, though Daniel still sometimes sees the yellow in his eyes.

Daniel also had a few bumps in his timing schedule. He started out by taking his pills in the morning. He remem-

bered the tip about attaching the pill-popping to something he does every day so that it becomes part of his routine. But he found that the morning didn’t work very well. “Taking the pills in the morning was a reminder that I have HIV, and that was a real downer at the beginning of the day,” he says. “And the side effects were bad, especially at the beginning, and I had

to suffer through them in the middle of the day when I was working. If I went out the night before, it was harder to take my pills in the morning. I’d want to sleep in, not get up and take them. So I decided to try taking them at night because then I would sleep through most of the side effects. I’m usually at home in the evening, so it was easy to do.”

Side effects were at the forefront of Daniel’s thoughts even when he was deciding on a course of action. His doctor gave him a couple of options for regimens and listed the potential side effects. Daniel wanted to avoid neurological side effects, so he stayed away from efavirenz (Sustiva); he figured the diarrhea and stomach upset of atazanavir would be easier to handle. His doctor had told him about the low risk of increased bilirubin, “but I freaked out when I saw my eyes,” Daniel says. “I didn’t think about how visible it would be. People asked me if I was OK. I acted surprised. What was I going to say? You don’t start revealing that sort of stuff.”

Daniel gives a lot of credit to the team at the local health clinic. Before starting HAART and for six months afterwards, he met with a nurse there to ask questions about his medical treatment and to talk about any feelings that arose. “I didn’t feel alone,” he says. “I felt supported and



agreed, but sometimes they didn’t. For example, 76 percent of doctors disagreed with the idea that drug side effects are worse than the disease itself; only 47 percent of PHAs disagreed that drug side effects are worse than HIV. This might be because doctors have knowledge of the advanced stages of HIV, while PHAs face the immediate distress of daily diarrhea or nausea.

And the reasons for delaying treatment varied too. Eighty-nine percent of doctors surveyed said the main reason for delaying treatment was that the patient’s CD4+ count and viral load did not warrant treatment. But only 27 percent of PHAs said this was their main reason—more important was the desire to avoid side effects (44 percent) and the fact that they were feeling healthy and didn’t have any symptoms (38 percent).

### *Adjusting the meds*

Once the decision to start HAART has been made, prescriptions are filled, pills are put in their dosettes, and the reality of daily pill-popping sets in. Like anything new, it takes some adjusting to take meds every day. But, as Daniel from Montreal puts it: “Adjust the meds to your life; don’t adjust your life to the meds.”

accompanied in my decision. It helped a lot to know the support was there. I felt more in control. For me, the biggest part of HIV is losing control of life. When I was told I had to start meds, I didn't feel that sick, and so I didn't feel in control because I wasn't even aware of the problem. The control came back when I learned my options."

The nurse at the clinic also offered a key piece of advice when Daniel mentioned that he wasn't going out at night because he had to be home to take his meds. She suggested he take his meds along with him in a small mint box. It was an easy solution that allowed Daniel to keep control of who knew he was taking meds and still permitted him to keep enjoying his social life.

For his part, Bill says he received one of the most important tips about how to stick to treatment on the day he decided to start therapy. He was in the elevator leaving his clinic in Montreal when a fellow passenger imparted these words: "Even if you are just going down to the store, take a dose with you. You never know when you'll meet friends who want to do something. At that moment, you don't want to have to rush home to get your meds." Since then, Bill always carries a dose of his meds with him.

More than 10 years after starting his first regimen of 3TC (Epivir), AZT and saquinavir (Invirase), Bill is still on the same combination. He's an anomaly and he knows it. He puts it down partly to good genetics and partly to his committed adherence. Currently, his CD4+ count is between 500 and 600 and his viral load is undetectable.

### **Gaining control**

Gaining a sense of control, like Daniel and Bill achieved with their scheduling tricks, is one of the goals of an innovative program at the Ottawa Hospital. Dr. Louise Balfour, a clinician and researcher at the hospital's HIV clinic, has designed a program to help PHAs get ready to take treatment before they start. The program, called STAART, includes four one-on-one sessions in which a psychologist and PHA discuss a range of topics around HAART. It covers pill-taking and strategies to keep on schedule as well as broader issues such as feelings about taking meds and better ways to communicate with others, including doctors. By providing information and tools, the program aims to better prepare PHAs for adherence challenges when they arise.

The program also includes a session on dealing with stress and depression. Depression is common among PHAs, affecting an estimated 25 percent to 40 percent. And

studies show a link between problems with adherence to HAART and depression. This makes sense given that many of the symptoms of depression, such as problems with concentration and memory and feelings of hopelessness (a sense of "why bother?"), could lead to difficulty with taking meds on schedule. Some of these symptoms are not what people normally think of as depression, so it's important to talk about them with your doctor.

Researchers have come up with a long list of things that can help or hinder adherence. Aspects of the regimen itself, such as daily number of doses, are obvious. Patient attitudes also reveal things that might be expected. A 2005 Canadian study noted that the confidence PHAs have in their ability to stick with the regimen and their optimism about taking meds were key to staying adherent. But clinical data on deeper issues, values such as sense of self-worth, are missing. "I think you have to like yourself," says

 Daniel

wasn't going out  
at night because he had  
to be home to take his meds.  
A nurse suggested he take his  
meds along with him in a  
small mint box.

Bill. "Self-respect has a lot to do with keeping up with adherence."

Bill says he's made taking his pills a priority. When asked about whether he has ever been in a spot where he just couldn't take his meds, he replies, "I've never gone through a period where my adherence faltered. Over and above everything else going on, I knew I had to take my pills."

ACCM's Gillian Kolla puts it this way: "You've got to build a good relationship with your meds." Like any long-term commitment, adherence to a HAART regimen involves respect, effort, negotiation and maybe a few slips along the way. But if you are prepared before starting your meds, the obstacles will seem a lot easier to navigate. Daniel and Bill are sure to agree—the payoff far outweighs the effort. +

David McLay, PhD, is staff writer/editor at CATIE in Toronto.

CALL FOR PARTICIPANTS: Dr. Bayoumi is looking for PHAs to participate in focus groups that are helping to develop the HIV treatment decision aid. He can be contacted at 416.864.5728.

# ASK THE EXPERTS

A regular department focusing on the most common treatment questions dealt with by CATIE's Treatment Information Educators.

## Gut Reactions

**“I recently started new meds and have developed diarrhea and general gastro-intestinal upset. It is terribly unpleasant and I am afraid that it will never go away. What should I do?”** —D.P., Medicine Hat, Alberta



ILLUSTRATION: PAUL GILLIGAN/IMAGEZOO

### MARIANNE HARRIS

Physician

BC Centre for Excellence in HIV/AIDS  
Vancouver

Gastro-intestinal (GI) upset and diarrhea are common side effects of many antiretroviral drugs. Luckily, they are often transient, resolving once your body gets used to the new medication. Here are a few suggestions to help you cope with these problems.

Check that you are taking the correct dose of your medications and at the right times with regard to food. If it is OK to take your meds with food, try taking them with or right after a meal. Some meds should be taken on an empty stomach, but given your GI

upset it may help to take even these meds with a light, low-fat snack, such as a few salted crackers, until your body adjusts.

For diarrhea, try adding fibre to your diet (whole grains, oat bran) or using a fibre supplement. The over-the-counter medication Imodium is often very effective; prescription anti-diarrheals (Lomotil or codeine) are an option in severe cases.

**FOR DIARRHEA,  
TRY ADDING FIBRE  
TO YOUR DIET.**

If you have nausea, try taking Gravol about 30 minutes before you take your meds.

For heartburn, antacids (Tums, Maalox) or acid reducers (Pepcid, Losec, Zantac) may be helpful; however, these drugs may reduce the absorption of some antiretrovirals, such as atazanavir (Reyataz), so check with your doctor or pharmacist before taking them.

If symptoms are very severe or if they persist, see your doctor as soon as possible. He or she will need to rule out other causes for your symptoms (such as infection, parasite or lactose intolerance) and may be able to switch you to a better-tolerated formulation or a new medication altogether.

### DANIELLE DESROCHES

Pharmacist

Clinique du quartier latin

Montreal

People with HIV often experience gastro-intestinal side effects, such as bleeding, nausea, vomiting and diarrhea, even without being on meds.

Highly active antiretroviral therapy (HAART) can often cause or exacerbate diarrhea in certain individuals but

**IT IS IMPORTANT THAT YOU CONSULT WITH YOUR DOCTOR AND PHARMACIST ABOUT WHAT APPROACH IS BEST FOR YOU.**

usually it is tolerable and transient, developing in the first two weeks of treatment and resolving within four to six weeks.

Diarrhea is common with all protease inhibitors as well as with tenofovir (Viread) and ddI (Videx), but because there are few restrictions on food consumption with these medications, it helps if you can take them with a meal. Those suffering these types of GI symptoms should also consider avoiding coffee, tea, carbonated

drinks, chocolate and alcohol as well as sugary, spicy or fatty foods.

There are several options for treatment. These include the following:

- 1,500 mg of oat fibre twice daily
- a supplement with psyllium, such as Metamucil
- 500 mg calcium carbonate twice daily
- pancreatic digestive enzymes such as Ultrase (a prescription is required)
- an anti-motility agent such as Imodium (over the counter) or Lomotil (prescription)

It is important that you consult with your doctor and pharmacist about what approach is best for you, to ensure no negative interactions with any other medication you're taking. Your doctor may also want to investigate further to eliminate any viral or other pathological causes.

### PAUL RICHARD SAUNDERS

Doctor of Naturopathic Medicine

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Naturopathic Medicine

Hamilton, Ontario

Patients should review their current medications as soon as possible with their prescribing doctor and see if new meds are causing these symptoms on their own or whether they are interacting with previous medications to produce these symptoms. Fluid loss can become a serious problem, so it is important to maintain fluids as well as electrolytes such as sodium, potassium and magnesium. Drinking water and broth soups can often be beneficial. Consider a high-quality probiotic with acidophilus and bifidobacter. The nausea may subside with ginger root tea or chamomile

**SEE IF NEW MEDS ARE CAUSING THESE SYMPTOMS ON THEIR OWN OR WHETHER THEY ARE INTERACTING WITH PREVIOUS MEDICATIONS.**

flower tea. Do not let this condition persist for any length of time.

### DEVAN NAMBIAR

Peer Counselor,

Treatment Information Educator

CATIE

Toronto

Most anti-HIV medications take two to nine weeks for the body to get used to. On a psychological level: minimize stress and get adequate sleep, light exercise and relaxation. Add foods high in soluble fibre, such as oatmeal, oat bran, fruit, barley and legumes.

**MINIMIZE STRESS AND GET ADEQUATE SLEEP, LIGHT EXERCISE AND RELAXATION.**

This will help improve digestion by providing more bulk for your GI system. Chew food slowly, avoid drinking liquids with meals—drink water/liquid a half hour before meals or an hour after meals.

Other options are:

- taking L-glutamine, which helps improve intestinal integrity and absorption of nutrients
- adding healthy bacteria such as acidophilus, bifidus, calcium supplements and digestive enzymes to improve digestion
- taking Omega 3 or 3-6-9 to minimize inflammation

If the intensity of the diarrhea does not decrease within two weeks, see your healthcare provider.

For more info on this topic, see *A Practical Guide to HIV Drug Side Effects* (pages 16–17). Read or order it at [www.catie.ca](http://www.catie.ca). Also, watch for CATIE's new *Practical Guide to Nutrition*, coming out this fall. +

CATIE staff is available to answer your questions (personally and in total confidentiality) at 1.800.263.1638 or through our Web site at [www.catie.ca](http://www.catie.ca).



# HIV-Positive? Supporting someone who is?

## CATIE is here for you

### In print, online and over the phone

The Canadian AIDS Treatment Information Exchange is Canada's national provider of treatment information in English and French to people living with HIV/AIDS, their care providers and community organizations.

CATIE is committed to improving the health and quality of life of all people living with HIV/AIDS in Canada, by providing accessible, accurate, unbiased and timely treatment information. Here's what we offer:

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Speak anonymously with one of our trained Treatment Information Educators about your treatment questions. Find out about local resources anywhere in Canada.

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■ **A Practical Guide to HIV Drug Side Effects:** What you need to know about various side effects related to treatment—from appetite loss to sexual difficulties—and tips for countering or preventing them.

■ **A Practical Guide to Complementary Therapies for People Living with HIV/AIDS:** An overview of many alternative therapies used by people living with HIV/AIDS, including massage, mind-body medicine and complementary medical systems.

■ **A Practical Guide to Herbal Therapies for People Living with HIV/AIDS:** An essential reference tool for people living with HIV/AIDS seeking information on understanding, choosing and using herbal medicines.

■ **Fact Sheets/Supplement Sheets:** Concise, credible overviews of a wide variety of specific conditions, symptoms, medications, side effects, complementary therapies and other topics of interest to people living with HIV/AIDS.

■ **Managing Your Health:** A must-read guide for people living with HIV/AIDS that addresses social, legal, health-related and practical issues comprehensively and from a national perspective. An outstanding primer.

■ **pre\*fix:** A harm-reduction booklet for HIV-positive drug users that includes information on safer injecting.

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

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# Vision Quest

An Aboriginal artist takes direction from the forefathers



Artist: **WABISHKI MYEENGUN**

(translation: White Wolf), 45

Toronto

Diagnosed with HIV in 2005

Artwork: *Watching Over*, 2007

18" x 24", acrylic on canvas

Every message I try to convey with my artwork has something to do with the old teachings that the Aboriginal people have acquired through the years. The main concepts I deal with are the teachings that come from the four directions—east, south, west and north. From each direction come different gifts and properties that contribute to the circle of life. Through my paintings, I try to teach people a bit about how our lives as Aboriginal people should be. We've lost our way but we're gaining it back, so I'm hoping that maybe my art can change things.

All my concepts are always about somebody helping somebody, such as my paintings where adults are teaching

children about harm reduction or safe sex. HIV affects my artwork a lot. It seems like I've matured all of a sudden and people are interested in what I'm trying to convey, which is mostly love and respect. Whether an individual has HIV, cancer or an addiction problem, love and respect can change things. That's what I try to portray in my paintings.

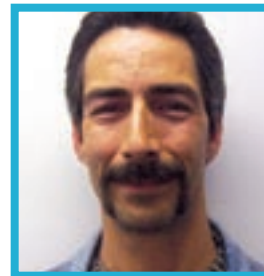
I love painting large canvases with acrylic paints. For the most part, my paintings are in colour because I dream in colour and it's vivid. Every painting I do is a vision that comes to me. That's what the Creator has given to me. Most of the time, if I see an image inside my heart the colours are already there; it's just a matter of me putting them in the right places. After the painting's done—and after an inexhaustible supply of pizza and medical marijuana—I sit down, look at it and say, "Wow! I did that!" I've developed my style over the past 20 years. I had formal training at Nova Scotia College of Art and Design. That was a good workout.

I'm an Aboriginal guy (Lakota and Ojibwa) going through my own healing process, trying to make it and take care of my family. I've got hepatitis C and cirrhosis of the liver (I used to be a bad boy), but I don't do conventional medicine. There are alternative medicines that are working for me. When my body's in pain, I make myself a nice marijuana tea that helps the pain subside, and it doesn't make me sick. I am so grateful to the Medical Compassion Clinic, which has been my foremost support since my diagnosis. When I hooked up with the clinic and got my medical marijuana license, it was the first step in my healing process.

Painting is an outlet and an expression for me. I believe that the forefathers are speaking to me through my painting. When I'm stressed, I take it out on my canvas and I come out with things that people really like. Hopefully, what I paint is going to touch somebody somewhere and that person will make a difference in the world as well.

I realize I'm not 10-foot tall and bullet-proof—I'm mortal. Having HIV makes me want to try a lot harder. I want to do as much good as I can with what I've been given before this thing takes me down and I'm not able to paint anymore. +

—as told to RonniLyn Pustil



art posi+ive is an initiative enabling HIV-positive visual artists to share their experiences of living with HIV through their artwork. The program was launched in 2005 by CATIE in partnership with Gilead Sciences Canada, Inc.

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