

THE POSITIVE SIDE

HEALTH INFORMATION & VIEWS

SUMMER 2013
VOLUME 15 ISSUE 2

RENAISSANCE MAN

Yves Brunet's
epic journey
with HIV

WHAT'S UP, DOC?

Why bedside
manners matter

IN GOOD SPIRITS

PHAs talk
spirituality

SPILLING THE BEANS

Telling others
you have HIV

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Answer a series of questions in advance to create a list of points to raise with your doctor.

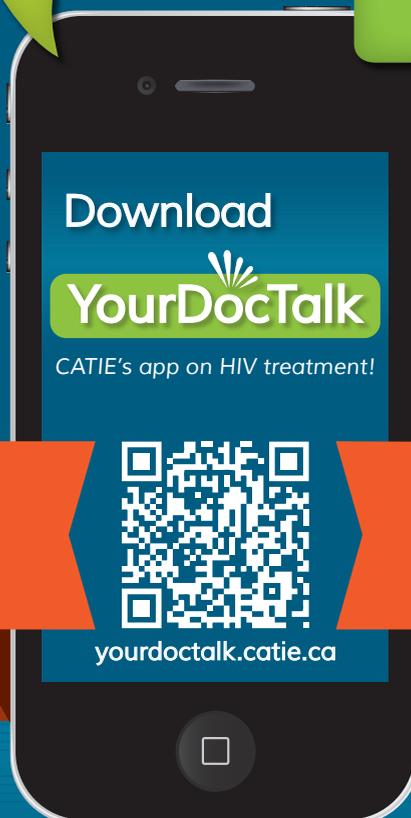
Together, you can work to ensure that your HIV treatment plan is right for you.

At my next appointment, I don't want to forget to mention...

How can I remember all my medical history?

When should I start treatment?

Is treatment right for me?



EDITOR'S LETTER

The current talk about HIV seems to focus a lot on the end of HIV. The media has reported on recent “cures.” Vaccine research has been re-invigorated. And the buzz about HIV treatment as a form of prevention continues to grow. Optimism is high and so it should be. Yet, it seems that sometimes this broader discussion misses the perspectives of people living with HIV.

For example, what is the impact of the growing interest in treatment as a form of prevention? The issue alters the way people approach HIV treatment decisions and how they think about sex. CATIE cannot provide all the answers, but we can help to ensure that the voices of people with HIV are part of the conversation. This issue's feature “Sex and the Serodiscordant” looks at the latest research on treatment, viral load and the sexual transmission of HIV. We share the stories of people who are using this info to come up with creative ways to keep their sex lives satisfying and safer.

In this issue, we also hear from people who have lived through much of the epidemic. We profile the experiences of two men who have been living with HIV for decades: Yves Brunet and Mike Holboom. Their stories remind us that in 2013 HIV still requires medical care (more on that topic in Chatty CATIE), that many people still need to adjust to life on meds (Ask the Experts tackles the subject of nausea and vomiting) and that staying healthy is something that takes an active commitment (Bob Leahy recounts how he quit smoking and we feature some health apps).

Yves' and Mike's stories also remind us that living well means supporting each other. Shari Margolese takes us on a very personal tour of disclosing HIV status. In “Spirit Matters,” three people talk about how their diverse forms of spirituality have anchored them and helped them help others. And our From the Front Lines column reports on peer support programs. Indeed, we all get by with a little help from our friends.

We welcome all your comments—your stars or your cherry bombs. Get in touch at dmclay@catie.ca. And enjoy summer!

—David McLay

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Peer to Peer

After an HIV diagnosis, the words of someone who has been there, done that are often the ones that help the most. It is with this in mind that we highlight peer-to-peer programs across the country.

BY MELISSA EGAN, WITH CONTRIBUTIONS BY SOPHIE WERTHEIMER



Peer Navigators

Positive Living BC and St. Paul's Hospital
Vancouver

At the AIDS service organization Positive Living BC and at St. Paul's Hospital's Infectious Diseases Clinic, peer navigators work one on one with people who are newly diagnosed as well as those who have been living with HIV for some time—to provide information, offer personal support and connect people to the services they need. Each client is matched up with a peer navigator based on shared histories and personalities. For many, this relationship becomes an important part of living well with HIV.

Peer navigators work hard to ensure that people don't get lost in the system, no matter their situation. They can accompany people with HIV to their doctor appointments or meet with them afterwards to answer questions. For some people, medical appointments can be loaded with anxiety. The presence of a peer helps ease the intimidation that many feel in a hospital environment and helps create a safe space where questions and fears are addressed by someone who's had similar experiences.

Peer navigators have extensive training in HIV treatment, management and prevention as well as harm reduction and reflective listening. These empathetic and understanding individuals are successfully creating links between marginalized individuals and clinicians, and improving health outcomes along the way.

To learn more, call 604.908.7710 or 604.682.2344 (ext. 63894) or visit www.positivelivingbc.org/service/peer-navigators

Positive Group Support Program

Maison Plein Cœur
Montreal

The chance to reflect on living with HIV and to support someone else through their journey takes a special individual and Maison Plein Cœur's Positive Group Support Program for HIV-positive men who have sex with men has many peer helpers who fit the bill. The program pairs people who are recently diagnosed with someone living with HIV who has had a chance to reflect on his experiences and receive training and support. This pairing helps to demystify the HIV experience and allows newly diagnosed people to see that even if their life is going to change significantly owing to their HIV, they can still live happily and healthfully.

The program combines support groups and discussions about topics like pleasure and safer sex with information about disclosure and treatment. Because GIPA (the greater involvement of people living with HIV/AIDS) is a core value of this AIDS service organization, peer helpers play a vital role in designing workshops, identifying discussion group topics and promoting the work of Maison Plein Cœur in clinics, gyms, bars and online.

Beyond information and support, this program is a source of hope and inspiration for many participants. Some arrive in distress and as they learn to manage their life with HIV and see other men who are living well with the virus, the desire to engage and help others takes hold. Some who initially receive support eventually become peer helpers themselves.

For more info, contact Vincent or Edith at 514.597.0554 or visit www.maisonpleincoeur.org





The Peer Support Outreach Program

AIDS Thunder Bay
Thunder Bay, Ontario

The peer support outreach workers at AIDS Thunder Bay spend much of their time reaching out to people who can be harder to reach. They connect with First Nations people, sex trade workers, youth and people who use injection drugs, distributing clean needles and safer crack kits and offering the support that only a peer can provide.

The past year has brought great success to this dynamic group. At Thunder Bay's Gay Pride events last summer, outreach workers introduced more than 150 people to the work of AIDS Thunder Bay. And later in the year, despite the rain, they connected with some of the people who were hardest hit by the city's flooding—distributing harm reduction supplies as well as food and bottles of water to help people through the city's state of emergency. These dedicated volunteers are considered invaluable to the work of this AIDS service organization.

To find out more, call 807.345.1516 or visit www.aidsthunderbay.org

Acute Peer-to-Peer Program

Regina Qu'Appelle Health Region
Regina, Saskatchewan

Launched in 2012 as a pilot project, the Acute Peer-to-Peer Program is now a well-established peer support program that continues to grow. The program's mentors have become a valuable part of the Regina Qu'Appelle Health Region's work to engage more people in HIV care and to help those newly diagnosed manage some of the daily challenges that come with living with HIV.

Mentors and mentees are often referred to the program by the Regina General Hospital Infectious Disease Clinic and Population and Public Health Services but are increasingly connected through word of mouth—a sure sign of how



successful the blend of community capacity-building and mentor training has been. As part of the mentors' extensive training, a local

psychologist has presented workshops on active listening, communication and assertiveness, and an infectious disease physician has provided HIV 101 education. The mentors share their experiences with mentees and support those who might be feeling isolated or intimidated. When a mentee feels ready, he or she can graduate from the program and move on to become a mentor.

For more info, contact Nicole Bachynski at Nicole.Bachynski@rqhealth.ca

Poz Gay Men's Group

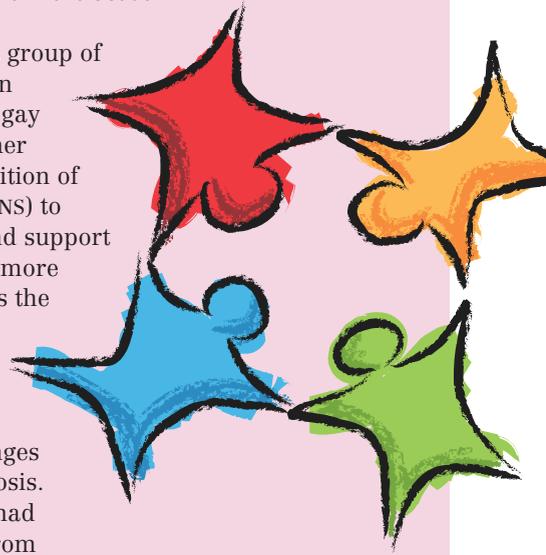
AIDS Coalition of Nova Scotia
Halifax

Once a month a group of HIV-positive men who identify as gay or bisexual gather at the AIDS Coalition of Nova Scotia (ACNS) to share stories and support each other. For more than three years the support group has been an anchor for many dealing with the challenges of an HIV diagnosis.

The group has had presentations from nurses, ACNS staff and even some of its own members who participate in national HIV initiatives and are then asked to share their experiences.

Those men who have been coming together for years are happy to offer people new to HIV guidance through complex hurdles such as disclosure, starting treatment and navigating the healthcare system. Lasting friendships have formed on these quiet evenings and while attendance tends to wax and wane with the ups and downs of life, a core group is always there to lean on.

To participate, contact Laura Toole at sc@acns.ns.ca



Mind Your Bedside Manners

Stories of kindness, compassion and crossing the line

INTERVIEWS BY RONNILYN PUSTIL



CHARLES DAWSON, 62

Charlottetown, PEI

Retired

HIV+ since: 1995

Last November I had to go to the hospital. The ambulance picked me up and when I got in, **the paramedic's first question was: "How did you contract HIV?"** I was in a lot of pain at the time and it caught me by surprise. I just looked him and said: "I don't think it's any of your business, is it?" He was taken aback. The other paramedic called him up to the front and about two minutes later he came back and apologized.

Later that night at the hospital, the nurse who signed me in asked me the same question. It was the first thing she asked. I gave her the same answer. She said that sometimes people "like to share" and I told her that it's up to me to share. The next day I talked to the head nurse about it. I told her that it struck me as kind of comical but some people might be bothered by it. The nurses I had after that were all fantastic.

In another incident, about four years ago, I was in the hospital because I was having a pancreatitis attack—they're not a lot of fun, let me tell you. The

doctor, who happened to be a woman, leaned over and said to me: "Well, that's what happens when you have homosexual sex." I laughed. I couldn't believe she said it! I thought, if you don't know better by now, lady, I can't be bothered. Getting mad wasn't going to do me any good.

I should add though that for every one of those, there have been 10 other healthcare providers who have been fantastic.

Message to healthcare providers: Don't judge people. These healthcare providers judged me before they knew my name. Put your prejudice aside, be professional and treat people with respect.

FRANCINE KELLY, 38

Kitchener, Ontario

Practical support worker, ACCKWA

(The AIDS Committee of Cambridge, Kitchener, Waterloo and Area)

HIV+ since: 2001

After my hysterectomy, I developed an abscess that led to my being admitted to the hospital. Due to health complications I was eventually brought to the ICU, where a resident treated me very poorly. I felt that I was neglected and discriminated against by this resident.

When I was transferred to a regular hospital room, **this resident disclosed my serostatus to friends of mine who were visiting me and didn't know that I was positive.**

I didn't want them to know. The room was full of people and he came in and started talking about my serostatus, asking me how long I've been on certain medications and is it because of HIV that I'm taking these medications. I replied "yes" and then I just

started crying. My daughter started crying, too.

There were four ladies in my hospital room that day. Two of them left the room and I've lost them as friends. The other two ladies, who had been coming to see me in the hospital on a daily basis, said that whatever they heard in the room would stay in the room, but since that day they have drifted.

I told the nurse what had happened and she told the resident's supervisor. Several people from the hospital came to talk to me about it, including a social worker. The resident came to my room, too, crying. He had no knowledge about what kind of impact his words would have on me. But now he realized that he had breached confidentiality. He said he was sorry and that he had learned a lesson. As a result of what he did, quite a few of my friends have drifted away with no explanation, and now I have to start working on how to deal with rejection and discrimination, as I have been excluded from social gatherings and church get-togethers.

Message to healthcare providers: Educate residents on the importance of privacy and confidentiality. And inform them about HIV and the impact it has on a person's life.



DOUG McCOLEMAN, 50

Montreal

Canadian co-chair of GNP+NA (Global Network of People Living with HIV, North America)

HIV+ since: 1985



In 2010, I had a mini stroke. There were no problems after that until August 2012. Based on the results of blood tests taken during a routine medical appointment, I was told to report to the Royal Victoria Hospital emergency room. It turns out that I had had a cardiac event. I spent a week in the ER while they tried to identify what had happened.

The Royal Vic is a teaching hospital, so troops of med students led by their professors arrived at my bedside several times a day. The profs presented me and invited their students to ask questions. On more than one occasion, I was asked: "How did you become infected with HIV?" At first I was speechless and then: "Well, I dunno. I'm not from an endemic country, nor am I an injection drug user, ex-prisoner or sex worker. I am gay, however, so my best guess would be sex. And how did you become infected with the flu the last time you had it?" The profs and some informed classmates were quick to straighten them out, though **at times I felt like an extra-terrestrial being studied.**

During this week of constant tests, I was denied food fairly often while I waited to be taken for these tests (which often ran behind schedule). Luckily, a nurse noticed this and told the support staff to ignore the orders given to them and to bring me food, with the understanding that I wouldn't

eat it until after my test. I started hiding the "unauthorized" food they brought me, to ensure they didn't take it away while I was gone. When my guardian angel nurse caught me doing this, she laughed and said it wasn't a bad idea. She also made sure to check that I had enough HIV meds and that I didn't forget to take them.

Message to healthcare providers: Teach med students that when a person with HIV is successfully treated, there is no risk to those providing us with healthcare services. A safe, nonjudgmental and collaborative environment in which people can disclose their serostatus is essential.

ROMARI, 58

Victoria, BC

Retired

HIV+ since: 1986

I remember one distressing encounter with a doctor who was filling in for my GP. I was concerned about some white patches in my mouth and wondered whether they might be related to antibiotic eye drops I'd been using for an infection. Within only a few minutes of discussion and after looking into my mouth, the doctor asked if I had any other health conditions. Upon answering that I was HIV positive, she very angrily asked: "Why didn't you tell me that when I walked into the room?" When I told her that I expected she would know this from my file, she said, "Don't waste a doctor's time by not telling them right away! Of course, you have thrush!"

The next time I saw my eye specialist, I asked if the antibiotic drops he had prescribed could have caused my symptoms. He said "absolutely." He had other patients, not HIV positive, who had also developed thrush-like symptoms from the medicine.

Over the years, I've experienced a wide range of side effects from my meds. Whenever I expressed to my specialist how miserable I was, he'd say something to the effect of "you just have to deal with it." About six years ago, when I was at death's door, my care was turned over to the Immunodeficiency Clinic at St. Paul's in Vancouver. I was resistant to many of

the antiretroviral drugs, and a new medication, not in full release at the time, was requested as part of a salvage treatment.

Having been told that I would probably go through a month of hell with side effects, initially I refused the drug. However, my son pleaded with me to please try this one last thing, so I did.

It turned out to be more like two months of hell. During this difficult time, I consistently received calls from the St. Paul's team, checking in on me. They were so understanding, supportive and encouraging that I continued taking the therapy while managing the side effects with their helpful suggestions. **Had it not been for their amazing support, I never would have made it through that point in my life.**



I now travel to St. Paul's every three months for my care. My health, both physically and emotionally, is the best it has been since my diagnosis. I credit the best in bedside manners for making the critical difference between my living or dying.

Message to healthcare providers: You are not only there to diagnose and prescribe, but to listen to our concerns, too. No matter how insignificant some of these may seem, they are important to our overall feelings of self-worth. The more we feel cared for and validated, the more we are healed. +

What supplement do you swear by? If you'd like to appear in the next Chatty CATIE, check the Contribute box on pg. 31, then drop us a line: contribute@positiveside.ca



La Mesure de l'Amour

Yves Brunet has been to hell and back. Here, he reveals how, after a seemingly endless string of hardships, he still has room for gratitude, humour and love.

PHOTOGRAPH BY RÉMI THÉRIAULT

I limp out of the dermatologist's office, where I just received two less-than-encouraging pieces of news. First, the doctor confirmed that I likely have metabolic syndrome. My psoriasis, which has made a comeback after a 10-year hiatus, is common in people with the syndrome. And, like many people with HIV who took anti-retroviral drugs during the late '90s, I have a number of symptoms that, together, define it—an accumulation of fat in the belly area, high triglycerides, low HDL (good cholesterol) and high blood pressure. I also learned that the pain in my foot and knee is likely due to a persistent condition called psoriatic arthritis, for which my treatment options (as a person with HIV and cardiovascular problems) are limited.

"Do I really need this?" I think to myself. I take a deep breath as I open the door of the taxi waiting to take me from Ottawa, where I live, across the river to Collège Saint-Alexandre, in Gatineau, Quebec, where I have been asked to tell my story. I have given personal testimonials many times before, but I take this time in the cab to review which anecdotes I will share today. I may be feeling low now but I know that speaking will lift my spirits, as it often does. I decide to start at the beginning.

In October 1986, at the age of 27, my then new partner suggested we get

tested for HIV before engaging in riskier sex. I was sure my test result would be negative. Three weeks later, my family doctor told me that I had tested positive for the virus that causes AIDS and that he had no idea how long I had to live, as there was no treatment available. "But you know," he said, "I could cross the street, get hit by a bus and die before you." Though that might have been true, it offered me little comfort. But it was what he said next that floored me: "And I will refer you to a psychiatrist to change your sexual orientation, as it is the cause of your infection."

Once home, I told a few friends, my parents and one of my three siblings. Then I went into isolation, though I continued to work every day as a human resources specialist with the now-defunct federal Department of Communications. I was petrified that people at work would find out.

Three years later, I was brushing my teeth one day and noticed on the side of my tongue some white stuff, which didn't go away when I tried to brush it off. I went to see my new doctor, who by then treated many people with HIV. He looked at it and said: "Oh, that's hairy leukoplakia." As a francophone, the only thing I heard was "hairy" and I certainly didn't want anything hairy on my tongue! He continued as if he was talking about the weather: "Oh, that's something that happens when one's immune system

is compromised." That sentence burst the bubble in which I had been moving around with crossed fingers, hoping I would not develop AIDS. Taking his diagnosis as evidence to the contrary, I took the money I had saved to buy a house, bought a round-the-world ticket and took off with a friend for three months.

Upon my return, I attended the funerals of nine friends over a three-year period. Not only was I losing people I cared about, I was going to the funerals of people who had died of the same thing I had, for which there was no effective treatment and no cure. It was emotionally draining, to say the least.

When my CD4 count hit 200, I decided to leave my job. I announced to my 88 colleagues, 21 of whom I managed, that I was HIV positive and approaching the AIDS stage of the disease and that I was going home to take care of myself.

Never mind Freedom 55, I was now retired at 34. That's fun for about three months, but I needed to find what I was meant to do if my time was limited.

Shortly after retiring, I began to feel stomach pain, and though I told my physicians, my complaints went nowhere. This is when I realized that doctors did not manage my health—I did! So I insisted on getting tests and

was diagnosed with cytomegalovirus (CMV) gastritis on December 15, 1995. I was put on intravenous treatment (Ganciclovir), on an outpatient basis, for 14 days. I asked my doctor innocently, “And then it will be gone?”

“No,” he said. “Afterwards, you will continue with the same treatment three times a week.”

“For what, a month?” I asked.

“No, for the rest of your life.”

“That raises an obvious question,” I said. “How long do people normally live with this condition?” I needed to know.

“Patients with your condition, on the medication we have now, live on average two years.” I thanked him for being frank.

A few months later, during a routine dental appointment, my dentist noticed a lump in my hard palate and suggested I show it to my HIV specialist. One week later they told me that I had Kaposi’s sarcoma (a kind of cancer that causes patches to grow on the skin, in the mouth or elsewhere in the bodies of people living with HIV who have very weakened immune systems). After 11 days of radiation treatment, I lost one-third of my moustache on one side. For the sake of symmetry, I shaved a third off the other side and ended up with a Hitler moustache for about three weeks. Other tumours sprang up on my neck and shoulders, but I chose to leave those alone for the time being and had them treated later.

Roughly two years after my diagnosis of CMV gastritis and AIDS, an ophthalmologist informed me that the virus in my stomach had decided to manifest itself in my eyes. He suggested I go for injections in the eyes to prevent CMV retinitis from doing more damage and causing blindness.

What choice did I have but to undergo the treatment, one for which sedation is not given lest the eye get scratched in the process? He told me that there was an experimental treatment in the U.S. where they put the patient to sleep (that sounded good already!), opened the eye and inserted a bag that released medication over a six-month period. “What happens

Before doing something, I would ask myself, “Is there love in this activity?” If there was, I would do it, and if not, I would move on.

at the end of the six months? Do they replace the bag, like with a vacuum cleaner?” The eye doctor hesitated and said: “We don’t know, we haven’t had a patient live that long.”

By March 1997, I had been on two protease inhibitors for over six months and my viral load was very high: over 721,000 copies. Not good. I tried a third one and—eureka!—my viral load plummeted. After four and a half months of weekly injections in the eyes, I no longer needed them. The IV treatments I received three times weekly over the course of two years also stopped. But instead of celebrating, I sank into a depression. My multiple losses—my job, my network of friends, my looks and some of my abilities—and my largely unacknowledged grief were all catching up with me.

Three years later, my retinas became detached and, after eight surgeries, the eye doctor informed me that I was legally blind, that nothing more could be done. I was given a form to get my white cane and another to be declared disabled according to the Income Tax Act.

For the first time in my life, I considered suicide. I asked Rob, my partner of 11 years, to help me do it. He said he would help me but that he needed some time. For me, time was equal to suffering, but I loved him and wanted to give him the time he needed. While waiting, I got used to my low vision and to the many tools that help people with it (my white

cane, magnifiers, special software, colour-coded measuring cups and spoons, among others).

Since then, I have had a heart attack and a stent put in. I am a poster boy for lipodystrophy. I also have DILS (diffuse infiltrative lymphocytosis syndrome), which involves the swelling of the parotid glands, giving me a chipmunk look for which I had unsuccessful radiation treatments.

But, somehow, life went on. Looking back, you could say that I had to reinvent my life. How? There was no sign from the sky above that told me what my new mission should be, but eventually, during my darkest days, I developed a tool I call *la mesure de l’amour*, which I used as a guide. Before doing something, I would ask myself, “Is there love in this activity?” If there was, I would do it, and if not, I would move on. I needed to know that whatever I was doing was either loving or helping somebody. I pictured digging a hole in the ground: I could either focus on the hole (what was missing) or concentrate on the mound of earth and what I could plant there.

When I have felt bad, I have tried to help others. There is nothing like it to make me feel better. So, I began facilitating support groups and organizing information sessions for other people living with HIV; I have also served on local and national boards (I’ve been on CATIE’s for the last seven years). Yes, I continue to deal with pain in my body and I take 18 different medications, but my health is generally much better. And when I sit down every night with Rob, now my husband, to enjoy a meal, I feel truly happy. My goal is to appreciate what I have and feel gratitude for every day.

As I pay the taxi driver, I feel ready to do my testimonial, to encourage people I have not yet met to open their hearts, and I realize it is not such a bad day after all. +

To get in touch with Yves, you can email him at yvesbrunet59@gmail.com

H E A L T H

O N T H E

G O

Wondering about your HIV treatment? How to quit smoking? Or when to take your meds? There's an app for that.

BY ERICA LEE

There seems to be an app for almost everything these days, and managing your health and HIV is no exception. Let's face it: Not everyone can afford a smartphone and not everybody wants one, but if you're the proud owner of one of these hand-held devices, here are a few free apps worth noting.

YourDocTalk

Whether you're thinking about starting or already on antiretroviral therapy, CATIE has a new app for you. YourDocTalk asks you a series of questions to identify the habits and health issues that may impact your HIV treatment options. Based on your answers, the app then creates a customized report that you can use to get the most out of your next treatment conversation with your doctor. It's quick and easy and your personal information remains completely confidential.

Available for iPhone, iPad and iPod touch.

www.catie.ca/en/treatment/yourdoctalk



Break It Off

If you're trying to quit smoking, this app from the Canadian Cancer Society can ease you through your break-up with cigarettes. Break It Off tracks your progress—the times you've resisted the urge for a smoke and the times you haven't. You get progress trophies during the good times, and distracting activities as well as the option of a toll-free call to a Quit Coach during the bad.

Available for iPhone, iPad, iPod touch and Android.

www.breakitoff.ca



iStayHealthy

iStayHealthy helps people with HIV monitor their health. Use it to chart your CD4 counts and viral load, as well as results from other blood tests, like your cholesterol levels. You can keep track of the meds you're on, side effects you've experienced and any doses you may have missed. There's also a place to record the contact info of your health clinics.

Last but not least, you can set up reminders telling you when it's time to take your meds.

Available for iPhone, iPad and Android.

www.istayhealthy.uk.com



<30 Days

The Heart and Stroke Foundation's <30 Days challenges you to improve your heart health in 30 days or less. Start off by answering some questions that help you identify habits that could put you at risk for heart disease and stroke. It's then up to you to meet daily challenges to improve your habits, such as squeezing in some extra exercise by getting off the bus one stop early and walking. The app offers reminders and awards your accomplishments as you work your way toward a healthier heart.

Available for iPhone, iPad and iPod touch.

www.heartandstroke.ca/YourRisk



Erica Lee is the Information Specialist at CATIE. She works in the health library field, supporting the information needs of frontline service providers and service users.



How to Say “I Quit”— and Mean It

Ex-smoker Bob Leahy
on how he butt out for good.

I'm an ex-smoker. When I smoked, I used to meet scores of fellow HIV-positive smokers, especially outside conference doors during breaks. I must admit that I enjoyed the camaraderie, the chance to connect with people, the ritual. I don't miss smoking but I do sometimes miss those often-chilly moments outside conference buildings where I made a lot of friends.

We smoke for a whole range of reasons. I took up smoking at the age of 30 because I had a boyfriend who smoked and I thought it looked sexy. The boyfriend came and went, but my two-pack-a-day habit lasted for a couple of decades. Menthol lights were my thing—who knows why? I liked the taste for a while, and then the habit took over and it became automatic to light up as soon as I woke up and then anytime my hands were free. I smoked one after the other, mindlessly.

When I was diagnosed with HIV in 1993, my smoking seemed the least of my troubles. Before the advent of effective anti-HIV therapy, people living with HIV typically had poor prospects for long-term survival and smoking offered a handy crutch, a stress reliever to blunt the edge of pain and depression. But with the introduction of protease inhibitors in 1996 and a vastly improved outlook—in fact, the prospect of many years of life to come—the rationale for smoking seemed to thin. Then, as more and more research showed strong connections between smoking and a long list of diseases and health conditions, not to mention a shortened lifespan, smoking became even less of a rational activity for people living with the virus, including myself. Nevertheless, smoking rates remain high in people living with HIV: Research indicates that more than 50 percent of people with HIV smoke, compared to 17 percent of the general population.

As I was living on disability support, it was eventually the cost of cigarettes that took my smoking habit down. Cigarettes were cheaper back then, but their cost still blew a major hole in my budget. They had to go. So I tried to stop, and failed. And tried again, and failed. And tried a third time, and failed yet again. Nicotine is highly addictive, so it's not uncommon to try quitting multiple times. But, says the Canadian Lung Association—and I think they're right—it gets easier each time.

My strategies for quitting were scattergun—cutting down gradually, chewing nicotine-replacement gum, using the patch, going cold turkey... I tried them all at one time or another. What felt like repeated failure was, of course, frustrating, but in retrospect each attempt helped me see what didn't work for me. By my fourth try, I had what proved to be the winning formula. By exposing what didn't work for me, quitting actually felt fairly easy.

My success finally came with knowing the simple truth that once you have quit, “having just one” doesn't work. The Canadian Lung Association says it's important to incorporate that knowledge into your plan. Pick a date to quit, choose a method (or two) and then “on your quit date, butt out completely. Don't smoke, not even a little. Toss out your cigarettes, other tobacco, and ashtray.” No cheating is the golden rule. It worked for me. The first few days were hard, obviously, but I knew I had a winning formula and so I stuck with it—and started liking how food tasted again. I felt proud.

There are a host of websites that offer other tips for quitting. I like “**10 Simple Tricks that Help Smokers Quit**” from caring.com, which recommends making your decision to quit public, tracking your progress on a calendar, exercising

Get Help Butting Out

- **10 Simple Tricks that Help Smokers Quit** – www.caring.com/articles/10-simple-tricks-to-stop-smoking
- **Smokers' HelpLine** (Canadian Cancer Society) – 1.877.513.5333 or www.smokershelpline.ca
- Apps, such as the Canadian Cancer Society's **Break It Off**
- To find out about the free quitline in your province or territory, call 1.866.366.3667 or visit the Government of Canada website www.healthycanadians.gc.ca/health-sante/tobacco-tabac/index-eng.php

For more resources, visit www.positiveside.ca

and chewing gum. The Canadian Cancer Society's online **Smokers' HelpLine** even includes a Quit Meter that lets you track how much money you are saving. And for hand-held devices, there are many apps out there, such as **Break It Off** (see pg. 11), which track your progress while providing supportive messages. In development are smoking cessation programs aimed specifically at people living with HIV—watch for them.

Whatever method you choose to kick the habit, it goes without saying that motivation is critical. Establish at the outset why you want to quit. We all know that smoking can kill, but did you know that researchers have reported that smoking has a more significant impact on the lifespan of people living with HIV than HIV-related factors do? Or maybe you want to avoid the host of health complications that smokers with HIV are at higher risk for—heart disease,

osteoporosis, lung and other cancers, gum disease, tuberculosis and emphysema, to name just a few. Of course, health problems that may be years away are not always enough to keep your motivation up, so consider the following:

- Smoking isn't really that sexy. A languid tendril of smoke may have a certain appeal, but bad breath and drooping erections do not good loving make.
- More non-smokers find the smell of smoke troublesome than ever before. Meanwhile, governments are placing more and more restrictions on tobacco use in public places and smokers are becoming increasingly stigmatized. Who needs more stigma?
- Smoking is expensive: The average Canadian smoker puffs 14.7 cigarettes per day and spends \$2,365 a year on tobacco products. Enough said.
- Once you've kicked the habit, food tastes better...and smells better, too.
- And you'll smell better! Your breath won't smell. Your clothes won't smell. Your fingers won't smell. Your hair won't smell.
- You will feel better about yourself (I certainly did) and people will respect you for what you have done.

As for determining the best time to quit, there is no time like the present. However, keep in mind that it is best to be fully prepared. Quitting isn't to be taken lightly—it's a major adjustment to your habits, your health and even how you feel about yourself. So take it seriously. Say “I quit” and mean it. +

Ex-smoker Bob Leahy is the editor of PositiveLite.com, Canada's online HIV magazine. He lives in rural Ontario with his partner of 32 years and three dogs, none of whom smoke.



Disclosing that you have HIV is something every person living with HIV struggles with. As **Shari Margolese** reports, careful planning and solid support can go a long way.

Breaking

M

My mother and two sisters sat beside me as I received the news over the phone that I had tested positive for HIV. They showered me with love and reminded me that they would always be there for me. Now I had to tell my father. My dad had warned me to “be careful out there” when I started dating after my divorce. I was terrified he would shun me or be disappointed. When I met with him, I got straight to the point: “Dad, I have some bad news: I just found out that I have HIV.” He reached out, took my hands in his and said, “Don’t worry, Shar. We’re going to get through this together.” I was surprised and relieved by his reaction, and for the most part he remained supportive until he passed away five years later.

Telling my father that I had been diagnosed with HIV was one of the hardest things I ever had to do. Since being diagnosed 20 years ago, I have disclosed my status to thousands of people. Some of those disclosures have been very public—on TV and radio and at major conferences. Others have been more personal—to family, friends and lovers. Even though most people have been supportive, it is the personal disclosures that have been the most stressful because of the fear of being rejected by those I care about most.

Since my diagnosis, I have seen dramatic changes. HIV used to be a death sentence; however, with appropriate treatment, people diagnosed with HIV today can live a nearly normal lifespan. And we’ve learned a lot about how to significantly reduce the risk of transmitting the virus. So that should make telling people that we have HIV a whole lot easier, right? Sadly, as too many people know, the stigma and discrimination surrounding HIV are still going strong. For many women and men, whether or not to disclose our HIV status remains one of the most difficult and daunting decisions. But most of us disclose anyways because there can be huge benefits: We can be supported, we can free ourselves of the burden of a secret, we can get the healthcare we need, we can talk with our sex partners about preventing transmission and we can educate ourselves and others.

Gordon, aged 60, and Jim, 55, a couple from rural southwestern Ontario have been together for more than 20 years. Both men are Native community workers who, like me, have been living with HIV for nearly two decades.

Gordon recalls that day, back in the early ’90s, when he received a phone call at work asking him to come in



the News

to receive the results of a series of medical tests he had recently undergone. He was told to bring someone with him. Because he knew few people in his new hometown of London, Ontario, and his boss was someone he felt he could trust, Gordon asked his boss to accompany him. That afternoon, Gordon learned he was positive.

While absorbing the news in the week that followed, he told nobody. The one person he intended to tell was his partner of one year, Jim, who at the time was living in another city. But for the moment, the only other person who knew was his boss. (In almost all cases, an employer does not need to know this information. See “A Hard Day’s Work” in the Winter 2012 issue of *The Positive Side* for more about disclosure at work.)

Days later, when the boss asked Gordon to work on the weekend, Gordon declined because he was already scheduled to work at his second job. The boss then proceeded to share Gordon’s secret with Jim, who he had met when Jim was in town and dropped Gordon off at work, and others. “Out of spite, he used the information against me,” Gordon says. “After my boss found out I had HIV, everything around me started to fall down like dominoes. One day I heard my co-workers talking about someone having AIDS and I

realized, ‘Wow, they’re talking about me.’” Gordon left his job shortly thereafter, feeling deeply betrayed by someone he had respected and trusted.

Gordon’s experience highlights two of the possible risks of disclosure: stigma and the chance that people will not respect your privacy. According to a 2013 report published by the Ontario HIV Treatment Network, other reasons that stop some people from disclosing their HIV status include feeling that they lack a strong social network, feeling ashamed and guilty about their status, homophobia and being concerned about burdening others. Nevertheless, research also suggests that in most situations, the significant benefits outweigh the risks and that most people feel little or no regret after disclosing.

Following this fiasco, Gordon eventually decided that if people were going to be part of his family and journey, he was going to tell them. His mom was immediately supportive but his dad took longer—at first bleaching everything Gordon touched. With the help of Gordon’s mom, his father eventually came around, as did many of his 27 siblings and half-siblings.

Telling Your Healthcare Providers

It's a good idea to disclose your HIV status to your **doctors** and **dentist** so they can provide you with suitable care. Knowing about your HIV and the medications you may be taking can help your doctors diagnose other conditions, help you avoid drug interactions and manage side effects. You may also want to tell your dentist because antiretroviral drugs and HIV can cause mouth and dental problems.

If you go for acupuncture, massage or other complementary therapies, you may choose to tell your **complementary health practitioners**, although this information should not affect the treatment you receive.

Healthcare professionals have a duty to maintain patient confidentiality. In most cases, it is considered professional misconduct if they disclose information you share with them without your consent.

Like Gordon's father and many of his siblings, people's reactions often evolve. It's worth remembering that upon hearing the news, some people might at first be shocked—even fearful, critical or angry—and need some time to digest it. Chances are that their initial reaction won't be their last. For Jim, who also tested positive, gaining the support of his family took time.

Shortly after he received the call from Gordon's boss in London telling him that Gordon was HIV positive, Jim got his own positive test result. He was devastated. He now faced the task of a double disclosure: telling his family that he was HIV positive and that he was gay. Although Jim feared he would be abandoned and ostracized, he gathered his parents, brother and sister together. Feeling defensive and fully expecting a homophobic, judgmental response from them, he braced himself and blurted out: "I'm gay and I have HIV. Deal with it." But he ultimately found support from his family, first from his brother, who was quick to squash gay and AIDS jokes at his factory workplace in defence of his brother, and later from his mom.

For the most part, if, when, where and how we disclose our status are personal choices. There is no one-size-fits-all roadmap to guide us. Instead, we need to judge each situation: Is this a person I want to disclose to? Will he or she keep what I tell them confidential? Or is this someone I can't really trust to have my best interests at heart? Research shows that in situations where we choose to tell, the more carefully we plan and prepare beforehand (see "Who, What, When, Where How and Why?" on page 17), the more likely we are to have a positive outcome.

Some people choose to start with a general conversation about HIV, to gauge a person's response. Many people

find it helpful to have pamphlets or phone numbers of local AIDS service organizations (ASOs) on hand so they can offer information to the person they're disclosing to. Trying to anticipate how the person you're telling might react can also help you plan how you will respond.

When it came to disclosing to his two sons, Jim was more careful. His sons, from a previous marriage, didn't learn that their dad was gay or HIV positive until later. "First they got to know Gordon as my friend," Jim says. Then the two men introduced the kids to other HIV-positive couples, including same-sex couples raising children. When the boys were 11 and 13 years old, Jim and Gordon took them to a retreat for families living with HIV. "We decided to tell them at the camp, where we could all get support and the boys could talk and share with peers in the same situation." The boys' response was typical for kids their age. One of them asked, "You aren't going to die, are you?" to which Jim responded, "Not if I have anything to do with it." Twenty years later, HIV is a non-issue with their now-adult kids.

When it comes to dating, everyone is different. Some people tell right away. Others wait to see if the relationship looks promising. Personally, I prefer to tell sooner rather than later for two reasons. First, my HIV status is widely known and a quick Google search would disclose on my behalf. Secondly, I want to protect myself. Even though I am generally very public about my status, it remains difficult to disclose in intimate situations. Putting it off can offer a reprieve, but it can also increase my anxiety and make it more difficult for the other person to accept.

Although who we choose to tell is mostly up to us, in Canada people with HIV have a legal duty to disclose their HIV status before sex that poses a "realistic possibility of HIV transmission" (see "Disclosure and the Law," opposite). Not disclosing your HIV status to sex partners can potentially lead to criminal charges. We can't go into the many issues around the criminalization of HIV non-disclosure and the different feelings they bring up—that would be a whole other article—but it is fair to say that these laws increase the anxiety that can come with the decision to disclose before having sex and in romantic relationships and that they make disclosure in general a much more complicated issue.

Since I have always disclosed to my partners, I didn't think that the criminalization of HIV non-disclosure would affect me—at least not until a recent medical appointment. I have always been open and honest with my doctor about my sexual activity, believing that if my doctor has all of the facts, she would be better equipped to provide me with the care and information that I need to stay healthy (see "Telling Your Healthcare Providers," above). The last time I visited my HIV clinic, I met a nurse I had never seen before. She asked if I was sexually active and if I knew my

Who, What, When, Where, How and Why?

To decide the pros and cons of disclosing in different situations, ask yourself:

- **Who do I want to tell? Who will support me?**

It is mostly up to you to decide who you tell about your HIV status. You don't have to tell:

- your employer or co-workers
- members of your sports teams
- people at school

It is, however, a good idea to tell your healthcare providers, including your dentist.

When it comes to sex partners, there are legal duties (for details, see "Disclosure and the Law").

- **What do I want to tell?**

You may, for example, want to tell certain people that you are living with HIV, but not how you acquired it.

- **When** and **where** do I want to tell?
- **How** do I want to tell?
- **Why** do I want to tell? How might telling affect my life and the lives of those around me?

Other people living with HIV and people who work at HIV clinics and ASOs can help you think through these questions and debrief with you afterwards.

partner's HIV status. When I told her that my partner was HIV negative, she asked me if I had disclosed to him. I told her that I had. She then said, "and you use condoms all of the time, right?"

The entire conversation with a complete stranger made me uncomfortable and her presumptuous question about condom use made me panic momentarily. Not knowing what would be done with the information I shared and feeling that it could somehow be used against me, I replied, "Of course, we use condoms all the time." As someone who has had an undetectable viral load for about 10 years, what I really wanted to do was to have an open discussion with her about the risks to myself and my partner if we did decide to have unprotected sex [for more on that, see "Sex and the Serodiscordant," on pg. 22].

After leaving the appointment, I felt angry. Once the nurse had established that my partner knew my status, I felt that should have been the end of her questioning and that it is up to me and my partner to decide whether or not we use condoms. A more open, non-judgmental approach would have been more helpful and would have created a safe space for me to ask questions and get support. I still believe that it's important to disclose all information to your healthcare team, but it is not always simple to decide just how much information you want to share and with whom. This experience caused me to worry that, ultimately,

criminalization can create a barrier to receiving the care and support we need to maintain healthy relationships.

Although the thought of disclosure might provoke anxiety, for many people the end result is positive—disclosure can bring friends and family into your circle of support. But it can also have serious negative impacts. For some, it can lead to the loss of "friends," rejection and in some cases even violence. If you have concerns about your emotional or physical safety when sharing your status, you may wish to:

- tell someone you trust (a close friend, relative, health-care or social service provider) that you intend to disclose so they can support you
- disclose in a public place
- bring someone with you

Disclosure is a journey, and everyone travels it differently. It often starts with tentative, angst-filled steps, and over time it can become easier in some situations while remaining difficult in others. Many people find that it grows easier to determine when it is best to keep it private and when it is better to tell. Carefully choosing when and to whom you disclose can take you from feeling anxious and isolated to feeling supported. And solid support can make all the difference. +

Shari Margolese advocates for people living with HIV to ensure that they have an opportunity to be meaningfully involved in the research, programming and policies that impact their lives. Shari is a regular contributor to *The Positive Side*.

Disclosure and the Law

In Canada, **you do have a legal duty to disclose** your HIV status to sex partners:

- before having vaginal, frontal or anal sex without a condom, regardless of your viral load; or
- before having vaginal, frontal or anal sex when your viral load is not undetectable (or not low), even if you use a condom.

You do not have a duty to disclose your HIV status before having **vaginal** sex if your viral load is low (or undetectable) **and** you use a condom. It is not clear whether this also applies to **frontal*** or **anal** sex.

It is not clear how the law applies to oral sex (with **or** without a condom) or to situations where the condom slips or breaks.

For more information, go to www.aidslaw.ca or check out chapter 21 of CATIE's *Managing Your Health* (available at www.catie.ca).

*The term "frontal sex" is sometimes used by trans men instead of "vaginal sex."



Spirit Matters

Many of us find meaning outside the worlds of religion and spirituality, but for some people living with HIV, their spirituality acts as a powerful source of inspiration and well-being.

BY JUDY PIKE

ILLUSTRATION BY AARON BIHARI

Tami Starlight was homeless and living on the streets in Vancouver's Downtown Eastside when she says she was lifted by a "power" bigger than herself, a power that knew that she "would be ready to respond." A Cree from Peguis First Nation, Starlight believes that she was born with a spirit but says her spirituality became "atrophied" when she was homeless and addicted to heroin, cocaine and other drugs.

Her spiritual renewal began in 1995, around the same time that Starlight, a trans woman, then 30 years old, was diagnosed with HIV. It took a few years, she says, but the drugs started to lose their grip on her life and her spiritual senses gradually grew stronger. By 1998, she was off the streets and off drugs. "My spirituality became my own when I got clean," she says.

Spirituality is sometimes described as an inner life, a moral compass, how you think, feel and behave in the

search for meaning. The exploration often begins with big, existential questions, as it did for Starlight: Who am I? Why am I here? How am I going to make my time here meaningful?

Many people who face a health crisis, including many people living with HIV, ask themselves such questions. For some, the answers can be found in religion. Others find meaning and purpose in the secular world—through nature, music or art, yoga or meditation, even psychotherapy or a commitment to social justice. No matter where it comes from, spirituality is, for many, a powerful source of personal strength and well-being. As Starlight, now 48, says, "Spirituality is that place, that part of my life that gives me great comfort."

Beyond comfort, research suggests that spirituality might also be good for your health. That may be because spirituality can bring with it a healthier lifestyle, community and

social support, less stress and better coping skills. Through nourishing their spirits, the people with HIV that we meet in this story connect with themselves and reach out to others. They cope with health and life challenges and draw strength to pursue their passions.

Following an HIV diagnosis, religion and spirituality can help people to examine the world from a fresh perspective and make sense of their new lives with HIV. That was certainly true for Starlight. Raised in Edmonton, she remembers going to church as a child. At 15, she left home and hitchhiked to Vancouver, where she eventually ended up on the streets for seven years. “I really lost my way and I attribute that to society,” she says. She cites environmental degradation and the pursuit of money and career as examples of practices that made it difficult for her to cope. The key to finding her way back, she says, was “reconciling [herself with] a lot of what people do.” That led to a process of “understanding why I had become what I had become, accepting and forgiving, living more in the now and being able to plan for the future.”

Starlight’s exploration to rediscover her spiritual self included returning to church. In the end, however, she found that she identified most closely with Aboriginal spirituality. For one, she says, there is “little or no dogma involved” in indigenous spirituality. “We [Aboriginal people] try to live in harmony with nature, and that’s where the Creator is.” Starlight says that spirituality is the “number one motivator for the things I do and how I navigate the society I live in.”

The medicine wheel, or circle of life, offers a fitting metaphor for the role of spirituality in the health and well-being of people living with HIV (see “As the Wheel Turns” in the Spring/Summer 2004 issue). Its four quadrants represent the physical, the emotional, the mental and the spiritual. Aboriginal elders say that if we are out of balance, it’s likely because we favour our mental and physical sides, pay too little attention to our spiritual selves and often don’t know how to express and deal with our emotions.

Diane Kaiswatum, an Elder from the Piapot First Nation near Regina, Saskatchewan, and a member of the board of directors of the Aboriginal AIDS service organization All Nations Hope, has counselled people living with HIV. Gentle and soft-spoken in her approach, she believes that we all

“I need to stop once a week and let myself be filled with awe and wonder through liturgy, silence, music, prayer and community.”

have a spiritual life, whether we call it that or not. Kaiswatum expresses her spirituality through Aboriginal ceremonies—whether through talking circles, smudging, pipe ceremonies or cleansing rituals, she says, they help people who have “fallen off balance” get back on track.

Her role as an Elder is to lead these ceremonies and impart her wisdom and experience to people who seek her counsel. She often recommends sweat lodges for people living with HIV: “They teach you when you get up in the morning, even before you put your feet on the floor, to give thanks for the day.” She believes that prayer and ceremony are particularly important for people with HIV because they provide comfort. No matter what we’re going through, she says, “we can’t be without prayer. We’re never to say that we don’t have anything, even at the lowest point in life. When you have prayer, you have lots.”

Ralph Wushke, 59, has been living with HIV since 1987. Deeply spiritual since he was a child, Wushke says that religion is his form of spirituality as well as his calling. He is the minister of Toronto’s Bathurst United Church and the ecumenical chaplain at the University of Toronto. “Whether as a person who is paid to be religious or not, my week would lose its sense of anchor if I didn’t go to a weekly church service and sing hymns,” he says. “I need to stop once a week and let myself be filled with awe and wonder through liturgy, silence, music, prayer and community.”

Raised on a farm in rural Saskatchewan, Wushke came to be more religious than his family. He says it’s hard to separate his spirituality from his homosexuality. “As an adolescent and closeted homosexual, I realized that religion and the church would be my way of making it in the world,” he says. “I saw it as a way to have a life as a gay person.” At the same time, his experience of religion is influenced by his homosexuality. “I’m religious because I’m gay but I’m also gay in a religious way. For example, love-making, sexuality, going to gay bars—I experience them all on a religious level.” In a gay bar, he feels a sense of community and a level of acceptance that he also finds in religion.

In 1995, Wushke was diagnosed with AIDS and went on long-term permanent disability. He describes his religious life as his “single greatest source of comfort” as he prepared for death, planned his funeral and wrote his will. Antiretroviral therapy then saved his life, but religion is what grounded him and gave his life meaning.

The elements of ritual and community, inherent in Aboriginal culture, are also aspects of many organized religions. Wushke points out that Judaism, Hinduism, Buddhism, Islam and Christianity all involve religious observances, laws and practices, including singing and gathering with a congregation. In our modern, increasingly secular society, he asks, “Why would people get together and sing those odd songs poorly for an hour every week? In fact, that’s still the way most of the world lives.” The answer, he says, is that there’s something very important about such practices. “They give you the opportunity to create social justice—along with the community, with the coffee, with the music, with the prayer. It’s a holistic experience.”

In a healthy religious community, Wushke says, you receive lots of emotional support. “Just at the level of managing your week-to-week crises, big or little, if you’re going to church, on Sunday morning there will be someone to listen to you,” he says. “It’s their duty to listen and care. If you don’t have that, you may be sitting alone with your problems. Community could be good for you.”

Spiritual meaning does not always take the form of religion or communal worship, however. It can also be more of a secular and independent experience. For Gordon W., a man in his early 60s living in Vancouver, his spiritual path started when he was introduced to mindfulness meditation. That was during a period he calls “The Dark Ages.” After his partner of 12 years was diagnosed with AIDS, Gordon’s life was in a state of turmoil. “On top of my own HIV diagnosis,” he says, “I was trying to help manage his disease and comfort him, while dealing with my own feelings of worry, fear, anger and grief.” His partner died in 1990 and two close friends also died of AIDS not long afterwards. Gordon needed something to help him cope.

That’s when he took off to Asia and discovered mindfulness meditation. Mindfulness meditation is based on Buddhist philosophy, but is not a religion, Gordon explains—it’s more a philosophy of living. And it’s open to everyone, regardless of their beliefs. His daily practice has taught him to notice his thoughts, feelings, actions and reactions. As a result, he no longer gets swept away by them or becomes disabled by them. “Mindfulness meditation teaches me to calm the mind and find a nurturing, safe and peaceful place.”

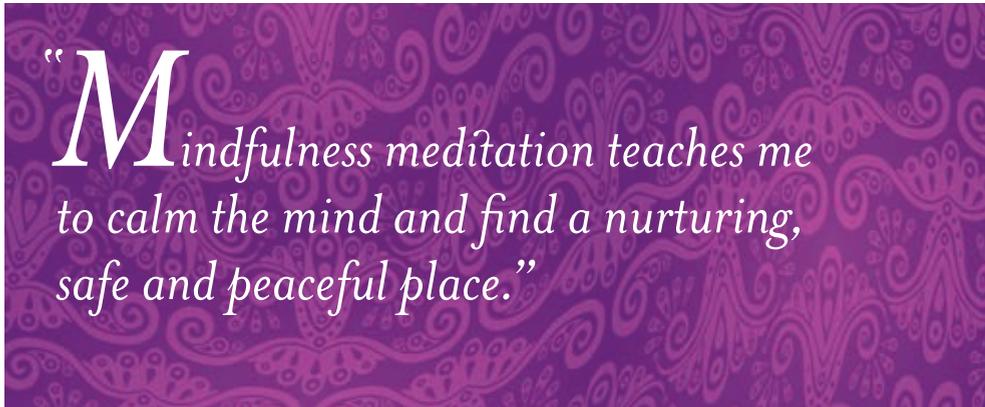
As a person living with HIV, Gordon describes how mindfulness meditation has helped him profoundly, not only spiritually but emotionally and physically too: “You gain consciousness and understanding on a subtle level of what’s happening in your body—everything from your muscle mass to your libido to your emotions—and what will help you.” Passionate about the benefits of his spiritual

practice, he says, “Mindfulness has given my mind, body and spirit the ideal environment in which to function.”

Researchers, too, have noted the health-promoting effects of what we call spirituality. Numerous studies have linked religion and spirituality to an improved ability to cope with a range of illnesses and stressful situations, having more of a sense of purpose, as well as a greater sense of overall well-being. Some even suggest a correlation between being spiritual or religious and improved immune function.

In addition to providing comfort, inspiration and a sense of well-being, Gordon’s Buddhist-inspired spirituality, Ralph’s religious faith and Starlight’s Aboriginal spirituality have led all three to reach out to others. Gordon now teaches Thai yoga massage, a wellness-promoting technique that combines moving, stretching and relaxation, and delivers workshops to both HIV-positive and HIV-negative people.

Beyond his work as a minister and university chaplain, Wushke is an unwavering advocate of environmental causes, world peace and social justice. He believes that one of his most important contributions to his community is as a chaplain counselling queer students, including those who are transgendered or two-spirited or new to Canada from parts of the world where it is a crime to be gay.



“Mindfulness meditation teaches me to calm the mind and find a nurturing, safe and peaceful place.”

Starlight has similarly devoted her life to advocating for social justice and societal change. She is a community organizer for numerous causes, including equality for transgendered people. Closer to home, she is an active member of the Downtown Eastside Neighbourhood Council, which advocates in the interest of residents. Her spirituality has helped her connect with people in a more meaningful way, she says. And connecting with people, as well as seeking equality and justice on their behalf, has become an expression of her spirituality: “My spirit compels me to get involved.” +

Judy Pike is an award-winning freelance writer and editor in Toronto, with a special interest in issues affecting people living with HIV.



Headlines about how a low viral load can cut the risk of HIV transmission lead many to wonder: “What do these findings mean for people living with HIV? And how do they affect my sex life?” CATIE’s **James Wilton** offers some answers.

ILLUSTRATIONS BY GREG STEVENSON

Sex and the Serodiscordant

Antiretroviral treatment has evolved dramatically since it first became available in 1996. Newer medications are more potent, less toxic and easier to take than ever before. With ongoing care, not only can people with HIV now expect to live almost as long and as healthily as people who are HIV negative, but recent research confirms what many scientists have long suspected: Treatment can dramatically reduce the risk of passing HIV to a sex partner. In a landmark study known as HPTN 052, HIV transmission was cut by 96% among *heterosexual* serodiscordant (positive/negative) couples if the HIV-positive partner was on treatment. So we now know that treatment can improve the health of people living with HIV **and** prevent HIV transmission.

These findings are changing the face of HIV and their significance is having a positive impact on many people living with the virus. John McCullagh, the publisher of PositiveLite.com—an online magazine by and for people living with HIV—and a member of CATIE’s board of directors, explains: “Having an undetectable viral load boosts my self-esteem and gives me a great sense of well-being. Apart from keeping me healthy, it lessens the burden of me worrying about transmitting HIV to someone else. It reduces the shame and fear of infecting others and this has had a positive impact on my life.”

Although successful treatment doesn’t eliminate the risk of transmission, our new knowledge means that undetectable HIV-positive people and their partners can

worry less about transmission, especially if they also use condoms. Given that condoms aren’t always foolproof, an undetectable viral load can offer an extra layer of protection in case a condom breaks or slips off. Some people are even choosing to not use condoms; however, the decision to have sex without a condom is an important one and needs to be made with a solid understanding of the evidence and risks.

YOU ASK, CATIE ANSWERS

Navigating what science has to say about treatment, viral load and HIV transmission can be challenging, and therefore simple answers are difficult to come by. What we do know is this:

- 1 Antiretroviral treatment—when taken every day, as prescribed—can over time lower a person’s viral load to undetectable levels.
- 2 A lower viral load in the blood generally means a lower risk of HIV transmission.

Beyond these basics, the information gets more complex and there are no cut-and-dried answers. Let’s look at some of the questions many people with HIV are asking:

How much does antiretroviral treatment reduce the risk of HIV transmission?

The HPTN 052 study showed that the risk of HIV transmission can be reduced by up to 96% for people living with HIV who are (a) in heterosexual relationships, (b) have

mostly vaginal sex, (c) go regularly for adherence counseling, viral load tests and STI (sexually transmitted infection) screening, and (d) receive free condoms and regular HIV prevention counselling. But it is not clear if this dramatically reduced risk would be the same for couples in the “real world” (outside of a clinical trial) who may not have access to these services or for couples who mostly have anal sex—

“Having an undetectable viral load boosts my self-esteem.”

namely, gay men and other men who have sex with men. It is expected that treatment has an effect but to what extent we don't yet know.

What is the risk of HIV transmission if my viral load is undetectable?

It's impossible to give a precise answer, but the general consensus is that the risk is *not* zero. That is because HIV is still present in bodily fluids even when a person's viral load is undetectable. (Undetectable does not mean that there is no virus in the blood, but rather that there is so little HIV present that available tests cannot detect it.) Also, research has found that when HIV is undetectable in a person's blood, there can sometimes be detectable (although lowered) levels of HIV in their rectal fluid, semen or vaginal fluid. This is concerning because it may increase the risk of HIV transmission, even when the blood viral load is undetectable.

Even so, the risk of transmission from vaginal sex in serodiscordant couples is likely very low under the following conditions:

- the viral load has been undetectable for at least six months;
- HIV medications are taken as prescribed;
- the HIV-positive partner goes for viral load testing regularly; and
- neither partner has an STI.

However, it can sometimes be challenging to ensure that neither partner has an STI. Because STIs can increase the risk of HIV transmission and some STIs may be symptom-free, screening and treatment for all STIs by both partners is important. For those in casual sexual relationships, consistent use of condoms combined with regular screening and treatment for STIs can help keep the risk of HIV transmission low.

What about anal sex?

The biggest grey area is around anal sex. We know that, on average, the risk of HIV transmission through receptive

anal sex can be 10 to 20 times higher than it is through vaginal sex. But that average includes people with high, low and undetectable viral loads. Is the risk still higher for anal sex when the viral load is known to be *undetectable*? Some experts think it might be but others, such as those at the British HIV Association, think it may be similar to the low risk for vaginal sex if the conditions listed above are met.

These uncertainties are important to consider when negotiating safer sex. However, it is undeniable that when one's viral load is undetectable (and other conditions are met), the risk of HIV transmission is dramatically lower. And this is having an effect on some people's sex lives.

PILLOW TALK

Open discussions can help sex partners agree on a safer-sex strategy. The topic of condom use is

one that comes up often. Stephanie Smith, from Gatineau, Quebec, who has been living with HIV since 2003, feels that talking openly with her partners has played an important role in having healthy sexual relationships and reducing the risk of transmission. “When I am in a new relationship, I tell my partner that I prefer using condoms,” she says. “I know the risk is really low when the viral load is undetectable, but there is still the chance of passing HIV. In my current relationship we use condoms all the time, but my previous partner really didn't enjoy using them. Since my viral load was undetectable, we went to the doctor together and discussed the risks and options. Based on that discussion, we decided to stop using condoms.”

For John McCullagh, who has been living with HIV for four years, decisions around safer sex also depend on the risk he and his partners are willing to take. “When I'm having sex with another positive guy,” he says, “I generally prefer to dispense with condoms. But when I have anal sex with negative guys, I'm very reluctant to do so without a condom, even though I am undetectable. In such instances, using condoms and having an undetectable viral load helps reduce the risk of HIV transmission to a level I am comfortable with.”

Telling your sex partner about your HIV status can open the door to talking about safer sex, but doing so isn't always easy. McCullagh hasn't always had good experiences. “Every time I have sex with someone new, we negotiate the kind of sex we want to have. It's a two-way street and we have to agree. It always starts with me disclosing my HIV status. Unfortunately, disclosure is difficult and doesn't always go well. There is a lot of rejection and stigma.” He points out that “for some people living with HIV, this means that they either don't disclose or don't have sex at all.”

One strategy to reduce the risk of rejection is to disclose as soon as possible, before feelings have formed. Nick, who has been living with HIV for 10 years and has

been undetectable since 2009, makes sure that prospective partners know his HIV status before they meet. “I am very upfront about my HIV status,” he says. “My online dating profile even says I am HIV positive. If a guy knows I am HIV positive before we meet up, there are no surprises and it reduces my risk of being rejected. It also means that he is probably more knowledgeable about HIV and open to talking about it. This makes it easier to discuss things like safer sex.”

EXTRA MEASURES

Whether or not condoms are used, there are several things that can be done to keep the risk of HIV transmission as low as possible when on treatment. The most important is to make sure the viral load in the blood is undetectable and stays that way. (In Canada, this level is normally 40 or 50 copies per ml of blood.) Scientists and doctors generally agree that your viral load should be undetectable for six months or more to minimize the risk of HIV transmission. Taking your medications every day exactly as prescribed is critical to getting your viral load to an undetectable level and keeping it there. If meds are missed, the viral load can increase, drug resistance can develop—leading to the need to switch HIV drugs and resulting in fewer drug options in the future—and the risk of HIV transmission can increase. Getting your viral load tested regularly can help ensure that the meds continue to suppress HIV. All of these things are also important for staying healthy.

Stephanie Rawson is a young HIV-positive woman who lives with her HIV-negative husband in Prince George, British Columbia. Her viral load is undetectable but she and her husband take extra steps to keep their HIV transmission risk low. “My partner and I use condoms when I am close to or on my period. This is because menstrual blood contains HIV even when the viral load is undetectable and can potentially increase our risk of transmission. I also make sure to take my meds regularly and get my blood work done every three months. If for some reason I forget to take my meds, we use condoms until the next time I get my blood work done, so that I know my viral load is still suppressed.”

Although having an undetectable viral load reduces the risk of HIV transmission, it is still possible for other STIs—such as gonorrhea, chlamydia, syphilis and herpes—to be transmitted. Whether it’s the HIV-positive or HIV-negative partner who has an infection, STIs increase the risk of HIV transmission, even when the viral load is undetectable. This means it’s important for both partners to look after their sexual health, get tested for STIs regularly and get appropriate vaccinations. Treating the STI as soon as possible and using condoms help to reduce the risk of STI and HIV transmission.

Nick combines having an undetectable viral load with additional strategies to reduce risk: “When I was single and with a guy who didn’t want to use condoms, I would minimize the risk by not ejaculating in my partner, using lots of lube and avoiding rough sex to reduce the chances of tearing. I also got tested regularly for STIs. I am now in a monogamous relationship with an HIV-negative guy. We are both STI-free and we use condoms most of the time, particularly if we’re engaging in sexual activities that could cause tearing. However, recently we didn’t use a condom and there was some tearing, so my partner started post-exposure prophylaxis (PEP). Now he’s thinking about starting pre-exposure prophylaxis (PrEP).”

Rawson feels that our new knowledge has had a positive impact on people’s sex lives. “People living with HIV have to deal with a lot of stigma, particularly when it comes to their sex lives,” she says. “Being undetectable allows my partner and me to have the sex we like to have and at the same time reduce our risk of HIV transmission. It has increased my sense of well-being and helps me feel less anxious and guilty about having sex.”

Nick believes he might not even be in his current relationship if it wasn’t for this new research. “Before me, my partner always said he would never date someone who is HIV positive because he was so worried about transmission.

STARTING TREATMENT

Most people with HIV start taking treatment at some point to improve their long-term health. For some people, HIV treatment can also be part of a plan to reduce the risk of passing HIV during sex (along with other strategies, such as condoms) and several treatment guidelines support this position. But the decision to start treatment rests with you, the person living with HIV. *You* need to be ready to start.

For the most up-to-date information on starting HIV treatment, visit www.catie.ca or call us at 1.800.263.1638 and discuss these issues with your doctor.

I think the understanding around undetectable viral load has put him at ease.”

The changing HIV landscape is good news for people living with HIV and their sex partners. Treatment turns out to be good not only for the physical health of people living with HIV but also for the health of their partners. By taking one’s meds consistently, getting viral load checkups regularly and looking after one’s physical and sexual health, the health of people living with HIV can be improved and the risk of HIV transmission reduced. Importantly, this helps reduce some of the fear, shame and stigma that some HIV-positive people experience when it comes to their sex lives and has a positive impact on their relationships as well as their mental and physical health. +

James Wilton is CATIE’s Biomedical Science of HIV Prevention Coordinator. He has an undergraduate degree in microbiology and immunology and is currently completing a master’s degree in epidemiology at the University of Toronto.

ASK THE EXPERTS

Get answers to your treatment questions



Nausea and Vomiting

"I've been living with HIV for the past 12 years. Lately, I often feel nauseous, sometimes even to the point of throwing up. Why, and what can I do?!"—A.J., Trois-Rivières, QC

INTERVIEWS BY PAULINE ANDERSON

TROY GRENNAN, MD

McMaster University Medical Centre (Hamilton) and Maple Leaf Medical Clinic (Toronto)

Nausea and vomiting can be caused by HIV alone, by an infection or by one or more of the medications that make up your antiretroviral therapy. It's crucial that your doctor determine whether there's a serious or reversible cause and address this early on, especially if you are throwing up repeatedly.

In the case of infections, a variety of bacteria (such as *E. coli*), viruses (such as Norwalk) and parasites (such as *Giardia*) can play a role. The strength of a person's immune system is one indicator of what the infecting organism might be. For example, if a person's CD4 count is low—an indication of weak immunity—the likelihood of an opportunistic infection (an infection that takes advantage

of a compromised immune system) is higher. However, simply because someone is HIV positive doesn't mean that his or her symptoms are due to a rare bug; often, the culprit is a common infection. This is especially true now, when having a severely compromised immune system is relatively rare thanks to the current, very effective antiretroviral medications.

If your doctor suspects an infection, he or she will take your complete medical history, focusing on potentially relevant exposures (for example, where you've travelled and what foods you've eaten recently), do a thorough physical exam and test for suspected infections. With appropriate treatment, most infections that cause gastrointestinal (GI) symptoms can be cleared up.

Medications are another major cause of nausea and vomiting. A wide range of medications, including

many HIV meds, have the potential to cause these side effects. Given that HIV-positive people typically take multiple medications, it's often hard to determine which one is the culprit. If the symptoms start soon after starting a particular medication, the new medication may be the cause. Symptoms often lessen over time, so your doctor may recommend waiting as a first strategy. Taking an anti-nausea medication can help during this period or may be used long-term in less severe cases. If the nausea and vomiting persist or are frequent or severe, your doctor may suggest replacing the medication most likely responsible for your symptoms with something else, to determine if this improves things.

In addition to infections and medications, there are many other potential culprits. To maximize your health and quality of life, it's important to keep members of your

Some drugs need to be taken on an empty stomach, but for those that don't, try taking them with food as this can make it easier to keep the medicine down.

healthcare team apprised of symptoms that concern you.

MICHELLE FOISY, PharmD
Northern Alberta Program,
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Many patients on the current crop of HIV drugs don't experience any nausea at all, and for others, the nausea tapers off after the first few weeks of being on treatment. But sometimes this symptom is more persistent, especially for people taking AZT (zidovudine, Retrovir and in Combivir and Trizivir) or certain protease inhibitors.

To address the nausea of people taking the protease inhibitor ritonavir (Norvir), typically used to boost other protease inhibitors, one option is to use the lowest recommended dose and to take the HIV drugs with food. For drugs that require a higher dose of ritonavir for boosting, switching to an alternate agent within the same class

or changing classes of drugs can often help. Changing the dose of ritonavir should only be done in consultation with a doctor knowledgeable about HIV treatment.

The nausea could also be caused by another medical condition, such as hepatitis. Or, it can be brought on by another medication that is interacting with an HIV medication.

Staggering the start of a full anti-retroviral regimen with that of medications for other conditions may help, as it avoids overwhelming the body with too many medicines at once. However, it's important that antiretrovirals be taken in their recommended combinations, as they attack the virus in different ways. The introduction of individual HIV meds should *not* be staggered because your body can become resistant to the drug in a relatively short time if it's taken alone.

For persistent cases, people can try taking an anti-nausea agent, such as Gravol (dimenhydrate). Other options include metoclopramide (Reglan), ondansetron (Zofran) and sometimes medicinal marijuana. Marijuana can also act as an appetite booster for people who have lost their appetite. Taking pills before bedtime might help in "sleeping off" the nausea.

Beware that if you take an antacid like Tums, ranitidine (Zantac) or omeprazole (Losec) for nausea or heartburn, this may lessen the efficacy of your HIV treatment. Be sure to talk to your doctor and pharmacist before taking any medication or supplement to avoid drug interactions.

PAUL SAUNDERS, ND
Dundas Naturopathic Centre,
Dundas, Ontario

When you take your medications can be important for avoiding nausea and stomach upset. Some drugs need to be taken on an empty stomach, but for those that don't, try taking them with food as this can make it easier to keep the medicine down.

Another tactic for managing nausea is to avoid certain foods, including

- spicy foods, such as chili
- dairy products, such as milk and cheese, which can cause acid reflux

- carbonated drinks, coffee and black tea
- too much sugar, which tends to produce stomach acid
- simple carbohydrates, such as white pasta, I recommend eating more whole grains, for example, barley or quinoa

Foods that may help settle the stomach include herbal teas—such as chamomile, mint and ginger—and catnip (which you can find in natural food stores). A thick puréed vegetable soup is not only nutritious but might also coat and calm the stomach.

As for herbs, I recommend slippery elm bark, available in health food stores. Mix the ground inner bark with cold water and chase that with another glass of water. It coats the lining of the esophagus and protects it from rebounding acid (acid reflux).

If you like the taste of licorice, try deglycyrrhized licorice (sometimes called DGL), either in capsule or lozenge form, which, again, coats and protects the stomach. In this form, the glycyrrhetic acid, which can raise blood pressure, has been removed. [To avoid drug interactions, always consult your doctor and pharmacist before taking DGL or any supplement, herb or medication.]

To improve digestion and boost appetite, I suggest drinking a glass of water with an added tablespoon of apple cider vinegar with meals. Or squeeze a lemon in warm water and drink that before eating. This tends to kick-start the taste buds. If you can find Swedish bitters, put a few drops in water and drink that before a meal. This, too, will help improve the taste of food.

Finally, I find that "mindful eating" always helps. Set aside enough time for meals, eat slowly and chew each bite well before swallowing, trying to make mealtime as enjoyable and calm as possible. It's all part of de-stressing around meal time, which relaxes the whole body, including the stomach. +

For more on managing nausea and vomiting, see CATIE's *Practical Guide to HIV Drug Side Effects*, available at www.catie.ca

Over the past three decades, Toronto's Mike Hoolboom has quietly become one of the most unique and respected experimental filmmakers in Canada, having created more than 50 films and videos that have garnered 30 awards at festivals around the world. A true artist, Hoolboom pushes creative boundaries by refusing to create films that tell us what to think and feel—instead, he wants viewers to have their own unique experiences.

Hoolboom's film *Positiv* (1998), the first of his six-part *Panic Bodies*, explores the dramatic and unsettling impact of HIV on his identity, his body and his relationships with friends and family. In the top quarter of a four-way split screen, Hoolboom's handsome face delivers a personal, unsentimental and often witty monologue about HIV, while a montage of intriguing and disorienting images in the remaining three screens symbolically and seamlessly reinforce his perspective. He begins by explaining how he no longer feels at home in his own body: "The yeast in my mouth is so bad it turns all my favourite foods, even chocolate-chocolate-chip ice cream, into a dull metallic taste, like licking a crowbar," he says, staring directly at the camera. "I know then that my body—my real body—is somewhere else, bungee jumping into mine shafts stuffed with chocolate wafers and whipped cream and blueberry pie and just having a good time, you know?"

I had the opportunity to talk to Mike about the making of this short film.

Jennifer McPhee: In *Positiv*, you let the audience in on what it's like to have HIV. What did you want to accomplish with this film?

Mike Hoolboom: *Positiv* was made a couple of years after the combination of anti-HIV drugs we called the cocktail arrived. It was part of the "afterlife"—the time I was never supposed to have. I had set every watch, reoriented every compass, staked every bet on the endgame—and watched with my doctors

the steady decline of my T4 cells. The march toward the end was measurable, quantifiable, almost reliable. I had a year left, maybe less, when the new [anti-HIV] drugs arrived. With them came a strange new set of disappointments: How could I forgive myself for outliving the contracted moment, particularly when so many others were dying simply because they were born in the wrong country? I had prepared so thoroughly and for so long for my death that I didn't know how to receive the unwanted gift of more and more time. I think the movie is a kind of grieving for the death I didn't have—though others might not read it that way.

Hoolboom's new film, *Buffalo Death Mask* (2013), takes viewers back to a moment, before antiretroviral therapy (ART) became available, when being HIV positive meant certain death. The movie opens to beautiful haunting music and the grainy black-and-white image of a death mask (a cast of a person's face following death). Seconds later, a gray human face that resembles the mask appears, alive now and looking at the camera. A conversation begins between Hoolboom and

artist Stephen Andrews (both men were diagnosed with HIV in the 1980s). While the two men open up to each other about their shared experience of almost dying, hazy light-drenched images appear onscreen. Andrews (who appeared on the cover of the Summer 2012 *Positive Side*) says: "I hadn't anticipated the difficulty of coming back from the brink. It took me three or four years to put Humpty Dumpty back together again. How do you start again from below zero?"

JM: With *Buffalo Death Mask*, what did you want people to understand about those years before ART?

MH: I had chanced across a roll of film exposed many years ago, showing a meeting of three friends in a small Buffalo apartment. When I slowed down the footage, I saw that light came from within their bodies, instead of falling onto them. This was something I had learned to see in the pre-cocktail years of being positive. Of course, I wasn't alone in this—many others opened their eyes in exactly the same way, at exactly the same time, like genius Canadian painter Stephen Andrews. He might have shot these figures

Candid Camera

Fringe filmmaker **Mike Hoolboom** shines a light on HIV.

BY JENNIFER MCPHEE



Still from *Positiv*, 1998.

himself, because that way of seeing glowing, luminescent bodies resides in his paintings, too. I can imagine that Stephen would put it differently, but that's the cover story I'm offering today. There is a light the body gives off when it's dying, and perhaps you can only see it when you're dying, or at least when you're dying you feel it in a very particular way. Everything is fading and aging and moving toward death, and this is carried in a particular kind of light. I wanted to show people what this looks like.

JM: In this latest film of yours, Stephen Andrews describes what was a common experience for HIV-positive people back then—watching a beloved partner die—yet your interview with Andrews is often humorous.

MH: Stephen is very funny! He could make a brick wall convulse with laughter. We touch upon some difficult moments, including the death of his partner Alex Wilson, who he had been with for 15 years. We talk about getting shingles, and nearly dying, and resenting others who are dying but not as fast as you are, and the whole while we are laughing our faces off. The laughing makes it possible to hold

“Movies offered a single irresistible promise: taking the place of the life I was too afraid to have.”

these stories, don't you find? Despair and depression are also popular options, but there was so much death at that time that we needed to blend up emotional cocktails along with the pharmaceutical ones, and these often included healthy doses of denial, deferral and gut-shaking laughter.

JM: You started filmmaking at the age of 20. What did you love about making movies back then?

MH: Movies offered a single irresistible promise: taking the place of the life I was too afraid to have.

JM: Have your reasons for making films changed?

MH: I've made movies for more than three decades now, though it is a medium for which I am particularly ill-suited. I am technically inept in a medium that still values some degree of machine esperanto. And my method is fundamentally unsound: I start at the edges, slowly filling in the frame from the corners until at last the outline of a figure is revealed at the heart of the matter. This requires a lot of time, and getting lost, and taking strange turns and tangents. So much is thrown away. It's very inefficient, and often what is revealed is so congested and mysterious that it is unreadable to anyone but my most cherished familiars. Or is it all right to make pictures for two or three friends? It makes me wonder, how many faces does it take to create an audience? +

To view *Positiv* and other Hoolboom movies, go to vimeo.com and search for Mike Hoolboom. For more on Hoolbooms's films and writings, visit www.mikehoolboom.com

Jennifer McPhee is a freelance writer who contributes regularly to *The Positive Side*.



A Woman's Voice

This picture was taken in Toronto as part of a research project I participated in. The project, called Visioning Health for Positive Aboriginal Women, brought together three groups of HIV-positive Aboriginal women from across the country to explore what health means to us. Our group took pictures and then discussed them. Many of us talked about how health is about more than just surviving, it's about thriving.

I took this picture of this girl and it looks like she's speaking. She looks proud and I think it's important for a woman to have a voice. I have a voice and I like voicing it. I'm proud of who I am. I think she's a beautiful woman—and so am I. She looks strong, she looks proud. I like to feel proud of who I am. HIV does not define me, but it's part of who I am, and that's OK. +

—Kerrigan B.

If you have a photo that you think could be the next Visual AIDS, send it to us along with a brief description of the story behind the image: contribute@positiveside.ca

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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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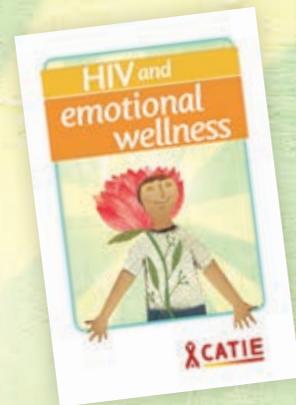


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