

THE POSITIVE SIDE

HEALTH INFORMATION & VIEWS

WINTER 2012
VOLUME 14 ISSUE 1

Former IDU
Chantale Perron
uses knowledge
to empower HIV+
drug users

WONDER WOMAN

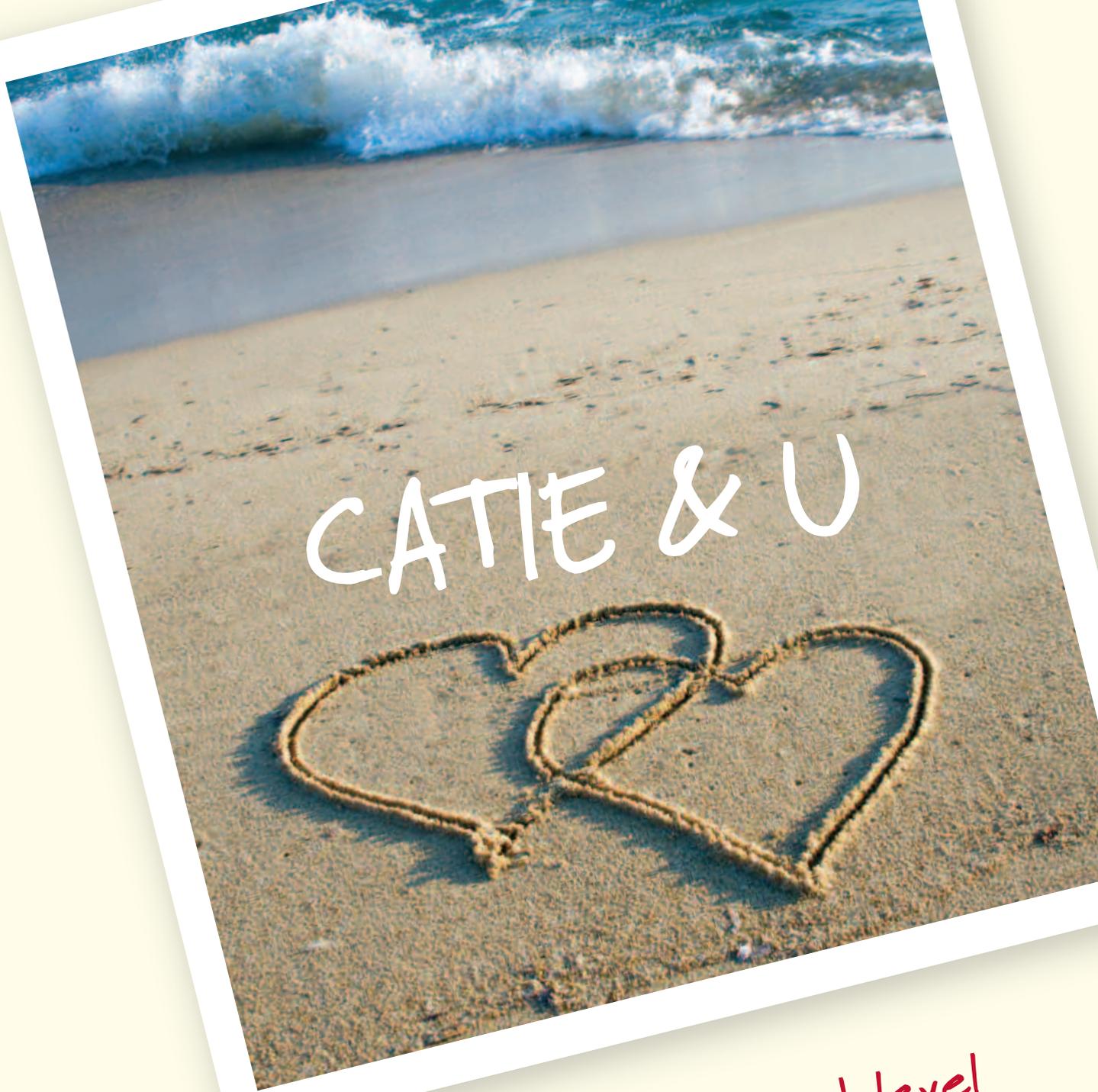
KISS AND TELL
Dating with the virus

GOT D?
*The lowdown on the
sunshine vitamin*

WORK IT OUT
On the job with HIV



Canada's source for
HIV and hepatitis C
information



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EDITOR'S LETTER

The more things change, the more they stay the same. That proverb seems apt for this issue of *The Positive Side*.

This past autumn, at CATIE's Knowledge Exchange Forum, I connected with many brilliant and dedicated people in the HIV and hepatitis C communities from across the country. I was struck by how the face of the HIV epidemic is changing in Canada. While sex is still a significant route of transmission, injection drug use is increasingly important in many regions. And drug use isn't happening just in our large cities—it reaches into small towns and rural communities coast to coast.

Chantale Perron, who rocks this issue's cover with her fantastic trademark locks, knows well HIV, hepatitis C and injection drug use. She found her passion fighting for the rights of people who use drugs. Perron and other activists lead the way, while the country slowly catches up.

Another change is that many people now expect to live long lives with HIV—lives that, for many, include working. And while we might kvetch about it, work can be a great source of fulfillment. But working with HIV has its challenges, as we learn in "A Hard Day's Work." In this article, we meet three people who juggle HIV, health and work to find security and satisfaction.

Change is also happening at *The Positive Side*. In this issue we announce an easier way for you to contribute to the magazine. We will be doing call-outs, specifically looking for people to appear in our Chatty CATIE column. Check out page 31 for details on how to let us know you want in.

One thing that's not changing? The good things we've got going on in these pages. You expect practical health information, and we deliver it. In this issue, we look at all the recent interest in vitamin D and what it means for people living with HIV. We provide an update and expert advice on kidney health. We also share some tips on how to assess online treatment information.

Things change, things stay the same. See what I mean?

—David McLay

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FROM THE FRONT LINES

What's happening across Canada

In Your Gay-bourhood

CATIE's Melissa Egan visits the organizations that are meeting the health needs of poz (and neg) gay and bi men.

For many years AIDS service organizations (ASOs) have strived to be everything to everyone, offering services that range from treatment support to social groups to food banks. And they have done an admirable job at it. However, these demands stretch an ASO's capacity, and new groups that serve specific communities are emerging.

Gay men's health organizations have been the first to open their doors, and in this issue, we're going to visit them. We'll also stop by a few ASOs that offer programs for positive and negative gay and bisexual men.



Gay ZONE

In response to rising rates of HIV and syphilis in the **Ottawa** area, diverse community organizations formed a coalition in 2007 to develop supportive and creative programming that would meet the health and wellness needs of gay men. And Gay ZONE was born.

This program is the "new kid" when it comes to taking a more holistic approach to gay men's health—and it's doing it very well. On Thursday nights, Gay ZONE offers an array of activities. Get a jump-start on the weekend by stretching out your muscles doing "Yoga with Loren" and then relax with a cup of coffee and chat with the charming outreach worker from the AIDS Committee of Ottawa. Give your brain a workout with the boisterous book club or take part in one of the youth-led evenings where young men discuss everything from flirting to disclosure to favourite brands of lube.

On the Gay ZONE website you'll find links to sexual health resources, trans and youth services, and an online tool you can use to notify partners if you've been exposed to a sexually transmitted infection. Pretty impressive for the "new kid."

www.gayzonegaie.ca



HEAT – HIV Education and Awareness Today

Still going strong after more than a decade, AIDS **Calgary's** HEAT program provides enthusiastic outreach, interactive education and information on condoms, lube and sexual health. While it still regularly hits the city's bars and bathhouses, the program has also expanded its activities to include the Alberta Rockies Gay Rodeo, Calgary's Pride festivities and the Fairy Tales Film Festival.

Putting the *reach* in outreach, the HEAT outreach worker has regular hours at the local bathhouse Goliath's. There, he teams up with the Safeworks harm reduction group to offer info on HIV/STIs and safer sex, referrals to support, along with confidential testing, vaccinations and other health services.

With a list of over 200 Facebook friends and friendly status updates that tell folks when and where to find him, the HEAT worker uses every means at his disposal to keep the community healthy, informed and connected.

www.aidscalgary.org

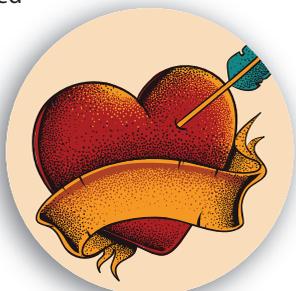
GUYZ – Gay Urban Youth Zone

GUYZ in **St. John's**, Newfoundland, offers integrated health services for gay and bi men between the ages of 19 and 29.

Organized by the AIDS Committee of Newfoundland and Labrador, GUYZ aims to build community among young gay and bi men in the city while empowering them to actively address their own health issues. There is a lot of talk about preventing HIV and hepatitis C. But the project also works to raise awareness of the prevalence of the two viruses and to provide info on living with HIV and hep C.

The guys at GUYZ are smart: They know they need to package all that important info with the other stuff that young gay men need to know about sex, sexuality and staying healthy. Cruising through their website reveals links to pages on masturbation, queer history, PFLAG and tips on how to make sure a piercing or tattoo studio is following safe procedures.

www.acnl.net/guyz





Poz Prevention Program – Toronto People With AIDS Foundation

“For us, by us” is how gay and bisexual poz men in **Toronto** describe this holistic sexual health program—HIV-positive guys draw inspiration and power from connecting with other poz guys.

The Poz Prevention program does outreach in local bathhouses, where program workers are open about their HIV status. Raising the issue of HIV in a sexually charged environment can lead to some intense conversations, so the program connects with TowelTalk, a local bathhouse-based counselling program hosted by the AIDS Committee of Toronto.

The Poz Prevention workers also connect with poz (and neg) guys on barebackRT.com, a website for men looking for unprotected sex. The outreach workers provide information and a space to talk about sexual health on a site where it can be difficult to do so.

Finally, the program’s monthly dinner and discussion attracts a crowd that is young, social and HIV positive. This is the place to go for people in Toronto who are looking for an alternative to some of the more established discussion groups.

www.pwatoronto.org

HiM – Health Initiative for Men



Health Initiative for Men (HiM) is at the front of the pack when it comes to taking a holistic and strength-based approach to gay men’s health in Canada. HiM operates a lively community clinic in **Vancouver**, where men can get tested for STIs, join a fitness group, go for counselling and more.

One unique service is the Personal Strategic Advisor program. Over six sessions, an advisor works with individual clients to alleviate stress and develop strategies to help them reach their goals.

This thriving organization started out as a program of AIDS Vancouver and has grown into a bustling urban health centre. Recognizing that gay men—poz and neg—face unique health challenges and providing a comprehensive and compassionate response has positioned HiM as a leader in the field.

This active agency has also made research a priority and has partnered with provincial and national research organizations.

Visit the HiM website for great blog posts, community connections, insights and updates on how to get involved.

www.checkhimout.ca



REZO

It’s hard to miss the REZO crew—smiling volunteers sporting stylish T-shirts with vibrant green logos—when they’re out and about in **Montreal**. This energetic and engaging organization (it won the jury prize for most crowd-pleasing float at Montreal’s 2011 pride parade) has been around for 20 years and has now taken on the task of promoting holistic health for HIV-positive and -negative gay and bi men.

REZO takes community building seriously and hopes to break down some of the barriers that isolate gay and bi men in the city. It focuses on offering support and encouraging gay guys to create connections that result in vital and satisfying social networks, which, in turn, promote health and well-being.

REZO’s programs and services include a ‘zine for male sex workers, coming-out discussion groups and workshops on topics ranging from serodiscordant relationships to quitting smoking. They also offer STI testing, and hepatitis A and B vaccination at local venues, such as bars and saunas. Keep your eyes open—these guys are everywhere!

www.rezonte.org

The Dating Game

The best pickup spots... when and how to disclose... the dates they won't soon forget. Four people with HIV kiss and tell.

INTERVIEWS BY RONNILYN PUSTIL



SÉBASTIEN GOULET, 38

Montreal

HIV+: 12 years

Job: Web services manager,

Fétiche Armada

Sign: Aquarius

Status: Single

LIKES: beards, leather, video games, zombies, nerdy guys, sci-fi, B-rated horror movies, glasses, bearded nerdy guys with glasses (maybe wearing leather)

DISLIKES: attitude, goat cheese (ugh!), bad breath, lack of compassion, elitists

How do you meet dates?

Usually via friends and sometimes in bars. **I've pretty much dropped all of the online websites due to rampant lying and serophobia.**

When do you tell a date that you have HIV?

My HIV status was very clear on my online profiles. As for an actual date, I usually tell the person on the second date. And I tell every potential sex partner before having sex.

Has disclosing ever led to a disaster date or a magical moment?

The disaster date is what prompts me to disclose to every potential

partner: I had met someone and we clicked really well. As we were kissing, he looked at me and asked: "Are you clean?" (I absolutely despise that term.) When I told him my status, he went into a giant panic and had to check his mouth for open sores. He said: "Thanks, now I need to go to a clinic." Baffling how a 35-year-old gay man still thinks HIV can be transmitted via kissing.

Does the HIV status of your date matter to you?

I prefer dating other HIV-positive men. As understanding and sweet and nice as someone can be, if they do not live with the disease, it's difficult for them to understand when you need to cancel a date because your meds aren't agreeing with you. Also, if I'm going to be in a long-term relationship, I'd rather not be the man who infects his partner if an accident happens with the condom.

The perfect date:

Definitely good food. Maybe a fun movie or an evening battling on the PS3. Lots of chatter about serious and inane things. And some heavy kissing, maybe beard rubs.

JESSICA WHITBREAD, 31

Toronto

HIV+: 10 years

Job: Youth support worker, Positive

Youth Outreach; grad student;

hairstylist

Sign: Taurus

Status: Separated (and loving it)

LIKES: Pomeranians, tea parties, vintage dresses, bicycles, hard-to-watch documentaries

DISLIKES: macho men, onions, mosquitoes, [Toronto Mayor] Rob Ford

How do you meet dates?

Mostly I meet people just from hanging out and through friends. My favourite places to meet dates are in the spots you're not looking for them—in the library or supermarket. Not that I pick up lots of people in the supermarket, but that's where the funniest conversations happen. Most recently I met someone on an airplane and now I have an international lover.

When do you tell a date that you have HIV?

That's a hard one. I generally go on a couple of dates and feel the person out a bit before disclosing. I tell before I know I'm going to make out with them. Ideally, they already know about the advocacy work I do, so they already know my status.

What is your disclosure approach?

I drop giant hints about the work I do so it's not coming out of left field. Then I cross my fingers that they ask me how I got into this work. Other than that, my style is to just throw it in like it doesn't matter—not like "brace yourself." I try to make it as cute and fun and playful as possible. I like to build up the sexual tension if I'm really into the person, and then I'll say, "I got the HIV."

Has disclosing ever led to a disaster date or a magical moment?

It's always been cool. I date men and women, and **I've never had someone kick me out of bed for being positive.** In fact, I find that they're more interested.



Does the HIV status of your date matter to you?

No, but I'm hard-pressed to find a positive person who wants to sleep with a lady.

The perfect date:

We ride our bikes to a park and have a picnic on a red-and-white-checked picnic blanket, with vintage china teacups and home-baked treats. There's lots of conversation with a definite make-out at the end. Or, a hot date with Freddy Mercury and we're both wearing jumpsuits (imagine how fun that would be).



STEVEN TINGLEY, 29

Toronto

HIV+: 8 years

Job: Actor, model

Sign: Aquarius

Status: Single

LIKES: big beautiful eyes, a great smile, a positive outlook, a sense of humour, charisma, walks on the beach, Chinese food, tattoos

DISLIKES: gossip, horror movies, sushi, lazy people, bad kissers

How do you meet dates?

One of my favourite ways to meet men is in clothing stores. I met one of my exes in Winners. I was walking down one aisle and he was looking at me over the clothing rack. We followed each other up and down the aisles, with strong eye contact the entire time, and then started a conversation in the checkout line. We were together for about three months. I've also met people at Athlete's World.

When do you tell a date that you have HIV?

I want them to see me for who I am, so I normally tell them on the first date. It's better to break the barrier right away than have your feelings hurt or be judged once you're in the relationship. Most people see it as a reward. They think, "He

told me right away, what a nice guy. That must have been hard for him." Many people are thankful because they don't usually ask before getting into bed.

Has disclosing ever led to a disaster date or a magical moment?

One gentleman and I met through a mutual friend, and I figured that since this friend was positive he might have disclosed my status. I hooked up with this guy and we started making out. When we went into the bedroom, I told him about my HIV status. He basically tripped over his pants and bolted through the door. His pants came off and he ran down the hallway in his boxers, freaking out. When he came back (his wallet was in his pants) we talked for a while. He really didn't know a lot about transmission. I settled him down and told him I'm on meds and I'm undetectable. He thanked me but said there was no way he could bring himself to be with someone with HIV. I never heard from him again.

Does the HIV status of your date matter to you?

No. **I've actually dated mostly negative guys. But I wouldn't want to infect anybody.**

The perfect date:

It's like a date I had a couple of weeks ago. We bumped into each other on the street and started walking together. We went out for supper and I ended up at his place. We chilled for a few hours—watching movies, talking, laughing and holding each other.

DANITA WAHPOSEWYAN, 44

Regina, Saskatchewan

HIV+: 5 years

Job: Needle exchange coordinator and peer support worker, AIDS Programs South Saskatchewan

Sign: Aquarius

Status: In a relationship

LIKES: going to movies, listening to music, relaxing, a man who likes kids

DISLIKES: poor hygiene, people who judge, spicy food, clingy or selfish people

How do you meet dates?

Usually through friends or relatives. I've met a few in the bar when I used to

go to certain clubs, but in a bar you don't really know who you're meeting; they could end up being a psychopath.

When do you tell a date that you have HIV?

I tell them right away on the first date if I really like them and wish to continue to see them. If I know there won't be a second date and it's not going to go any further, I don't feel the need to tell them.

What's your disclosure approach?

I've been in the news and I work at an AIDS organization, so most people already know that I am positive. But if they don't, I'm usually very upfront about it.

Has disclosing ever led to a disaster date or a magical moment?

I told my current boyfriend that I really liked him and that there was something about me that he should know if we were to continue our relationship. He was very kind and nonjudgmental.

Does your date's HIV status matter to you?

No. Why should it? **People are people, and some things you just can't change about a person.**



The perfect date:

He comes to pick me up with a bouquet of flowers and takes me somewhere nice for dinner. Then he takes me to a movie or park and we hold hands and talk about the future together. +

Want to talk about your tattoo? Or praise your pet? Go to page 31 to find out how you can appear in Chatty CATIE.



Inspiring Devoted Unstoppable

Despite the devastating loss of her *grand amour*, **Chantale Perron** is as determined as ever to support and fight for the rights of drug users and people with HIV.

PHOTOGRAPH BY PIERRE DALPÉ

I started injecting heroin when I was 17 years old. When I was using, I went for HIV tests two to three times a year. Each time I visited the clinic, they would ask me: Had I been involved in high-risk activities, like sharing needles or having unprotected sex? Each time I answered the questions and each time I would find out later that I had tested negative. Then, one day in 1992, when I was 24 years old, they called to tell me that my test result had come back positive. I'd been sharing needles but the words floored me nonetheless.

I thought my life was over—that nobody would talk to me again, I would never have another boyfriend, I would never find a job or have a family. I was sure this was the end. I tried to stop using but I was in such a daze that I couldn't.

Somehow, life kept going. The first person I told about my HIV status was my mom. She had always worried about the needles and that I would get HIV. Then I told my friends. All of them were supportive; nobody rejected me as I had feared they would.

Strange as it may sound, the terrible news brought about some positive things: It strengthened my relationships with my friends and family. Two years after being diagnosed with HIV and subsequently hepatitis C (my doctor reassured me, as was common in those days, that hep C wasn't serious), I started taking methadone and stopped using drugs. And I started to work on myself and my life. I had always suffered from low self-esteem and had always done everything I could to please people—especially men. Following my diagnosis, I strove

to become a proud, strong woman who spoke her mind.

A few years after my diagnosis, I started getting involved in community work, first as a volunteer and later as an employee. When I started volunteering at GEIPSI (*Groupe d'entraide à l'intention des personnes séropositives et itinérantes*), a Montreal organization that helps substance users turn their lives around, I met a guy who was also HIV and hep C positive. I worked in the basement of the group home and Stéphane was one of the residents living upstairs. A coworker had given him two theatre tickets, and he asked if I wanted to see the play with him. Most people thought that two former drug users with HIV and hep C spelled bad news. (I had stopped using just one

year earlier and Stéphane had been clean for only a couple of months.) But we went to the play and started dating. One thing led to another, and we ended up sharing our lives and love for 12 years.

From 1998 to 2002, I worked for CPAVIH (*Info-traitements du comité des personnes atteintes du VIH du Québec*). While providing people with information on HIV, I discovered a talent for communicating and explaining complex issues to people in simple terms.

In 2001, I started publishing *Pusher d'Infos*, Quebec's first magazine by and for drug users. Though it is now defunct, to this day drug users tell me how much they liked it. I also wrote hundreds of articles for various publications to share what I had learned at national and international conferences. That job allowed me to realize my full potential while helping drug users and people living with HIV and hep C. In the process, I discovered the activist in me.

I had always had an activist spirit but when I started defending the rights of drug users and people with HIV, I found the channel I had been missing. I participated in demonstrations, signed petitions and lobbied funders and policymakers to make decisions needed to improve our lives.

Because I used heroin for more than a decade and I work with drug users every day, I am able to connect with them. I tell them: "You're still a human being and a citizen. You might be a user, but you can still have goals and you have the right to voice your opinions."

Since recovering from the initial shock of my HIV diagnosis and up until this point, the fact that I was HIV positive had had little effect on my life. I started taking antiretrovirals in 1996 and took the same medications up until recently. Minor side effects, such as headaches and dry mouth, had been the only noticeable signs of HIV and antiretrovirals in my life.

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The fact that I had worked hard on myself and changed over the course of many drug treatment programs, that I had a job where I felt useful and my potential was realized and, most of all, that I had found someone who was both a friend and lover made for a rich and fulfilling life. Of course, it wasn't perfect, but overall, even with its ups and downs, life rolled along pretty smoothly for 12 years.

Then Stéphane started to have problems because of his hepatitis C. His health deteriorated quickly over the next two years. I devoted myself completely to his well-being and tried to be there as much as I could for him. During that time, I paid little attention to my own health. I continued to work but spent the rest of my time taking care of Stéphane, accompanying him to countless medical appointments and doing whatever I could to lessen his suffering.

I acted strong and fearless in front of him, but deep inside I was terrified and heartbroken. Then, in 2008, Stéphane passed away. He had just turned 40.

That was three years ago. It took me three years to cry and mourn, to come out of my depression and regain my health (or most of it, anyway), which had deteriorated when my love passed away.

As if time had stood still while I took care of him, the weight of those years caught up with me when he passed. I fell into a state of extreme exhaustion. I had to stop working and, within a few weeks, I no longer had the energy to walk around the block or make my own meals. Suddenly, I gained weight, wrinkles lined my face and dark circles appeared under my eyes. I had aged 10 years. Since then, I've had to learn how to manage a chronic fatigue that limits everything I do.

It was with great effort that I managed to carry on, thanks mainly to my family and close friends. I never could have made it without them. During some of the rough patches, the only thing that allowed me to put one foot in front of the other was knowing they were there for me.

My health has improved dramatically, though it's only around 75 percent of what it was. I have embarked on a new chapter, both in my personal life and my work life. For the last four years, I have been working at *Méta d'Âme*, an organization run by and for people addicted to opioids. Working at the drop-in centre and with the 22 residents, I feel that I am making a difference. I adore this work, where I am lucky to be surrounded by friends every day.

Today, I am 45 years old. Wow! Back in 1992, I thought I had barely two years left to live, and here I am about to reach a milestone: 20 years of living with HIV.

I am now starting to enjoy some of the pleasures of single life. I find myself doing things I've never done before—small stuff, like going on a whim to see a movie at night or trying a new restaurant. To me, this curiosity is a sign that I am still very much alive. +

Sizing Up Web Sources

6 tips for assessing the credibility of online health info

BY LAUREN PLEWS



On the Web we have access to more health information than we could ever use. So how do we know we have the best information and that we can trust it? What do we look for when deciding what to trust? In a word: credibility. For something to be credible, the source needs to be both reliable and informative. Below is a list of six questions to keep in mind when visiting a health-related website for the first time.

WEBSITE CHECKLIST: 6 KEY QUESTIONS

1 Is the site clear about its purpose or goal?

Websites are created for all kinds of reasons. Some are meant to inform, while others state an opinion. The purpose of many sites is to promote or sell a product or service. It is important that a site tell you exactly what it is trying to do and why.

2 Is the site what it claims to be? Does it do what it claims to do?

If the website says it has everything on a topic—say, HIV treatment—check to see if it has enough information to support the claim. If the site does not

mention, for example, the latest anti-HIV drugs, it is not living up to its claim.

3 Is it easy to find out who is responsible for the site and how to contact them?

Ask yourself questions such as: What is the background or credentials of the website's creators? Can you find information about the organization, such as its history, staff, board and location? If you can't find any way to contact the site's creators, this is a red flag.

4 Is it clear when the information was created or updated?

Health information—especially HIV information—is constantly changing, so the website should be up-to-date, as should the links to resources and other sites. A website that hasn't been updated in a long time may not be the best source of information (although there may be exceptions).

5 Is the information presented in a way that informs you? Or does it try to persuade you?

The website should present information in a balanced way. If you

feel more like the site is trying to convince you of something, think twice before taking it as fact.

6 Are sources given when facts are presented?

Facts should be separated from opinion, and the sources of facts should be provided. Some Web content may not be held to the same standards as newspapers or science journals. Fortunately, there are many websites that do follow high standards.

Ask yourself these six questions when you come across a new website. If it doesn't meet your standards, keep surfing. If you find something great, bookmark it. +

DON'T JUDGE A SITE BY ITS DESIGN

A great deal of research has been done to understand how users evaluate websites. A site that looks more professional or well designed will be seen as more credible. The risk in this is that the information is not being evaluated, so it is important to look carefully at the content.



Daily Dose of



Here in the “True North,” getting enough vitamin D—the sunshine vitamin—is especially important for people with HIV.

BY R. PAUL KERSTON

Living in Canada, one may muse over (and maybe even complain about) the lack of sunlight, especially in winter. In Vancouver, where I live, the average number of daylight hours on December 22 is one half of what we get on June 21: 8.04 hours compared to 16.23. But who’s counting?

Besides making it harder to get out and get active, that lack of sunlight during winter can have health impacts, including lower levels of vitamin D—which the body produces in response to sunlight. You’ve likely heard news stories in the past few years about research into the sunshine vitamin’s role in health. Low levels of vitamin D have been linked to many medical conditions, but what does all this research mean for people with HIV living in Canada? While there is much left to learn, researchers are finding that people with HIV need to make sure they are getting enough vitamin D.

IDENTI-D

Classified as a vitamin through the happenstance of history, vitamin D is actually a hormone, meaning that it acts as a chemical messenger in the body and is important for

regulating many chemical activities in cells. We know for sure that it is involved in bone health. It also helps with the absorption of the bone-building minerals calcium and phosphorus from the intestines.

Clues for where else vitamin D may act in the body come from where receptors for the vitamin are located. Based on the location of those receptors, vitamin D may be involved in muscle, brain and liver function. Those receptors are also found on immune cells, such as CD4 cells and macrophages, leading researchers to speculate that vitamin D may play a role in immunity.

The body can produce vitamin D in a multi-step pathway that starts in the skin, where heat from sunrays kicks off the process. The liver and the kidneys work next, transforming intermediate forms, called vitamin D₂ and vitamin D₃, into the active form of the vitamin, calcitriol. Blood tests vary in what form of vitamin D they measure. The most common test measures total vitamin D₂ and D₃.

There is debate over ideal blood levels of vitamin D. Based on studies of bone health and blood levels of calcium and parathyroid hormone, the American Endocrine Society

suggests that the results of vitamin D blood tests be interpreted in this way:

- 75 nmol/l or higher is sufficient
- between 50 and 74 nmol/l is insufficient
- 49 nmol/l or less is deficient

According to a 2009 Statistics Canada study, about one-third of Canadians had sufficient levels of vitamin D. The same study indicated that one in 10 people were deficient. (Note that the study used an older, lower cut-off of less than 37.5 nmol/l to define deficiency.)

Not being exposed to enough sun or wearing sunscreen (which blocks the formation of vitamin D in the skin) can lead to inadequate levels of vitamin D. Other factors that can put people at risk for deficiency include obesity (having a BMI higher than 30), older age and health conditions such as liver and kidney damage or inflammation of the intestines (Crohn's disease, for example).

LESS D WITH HIV?

Scientists are beginning to think that HIV, perhaps through its associated ongoing inflammation, might also change how well the body can produce vitamin D. There is no clear evidence that vitamin D deficiency is more common in people living with HIV than in HIV-negative people. However, in a recent large cohort study of people with HIV in Europe, Argentina and Israel, only one in 10 (11 percent) had vitamin D levels above 75 nmol/l.

In the trial, most (82 percent) of the people were taking antiretroviral therapy (ART). This is of note because some anti-HIV drugs may affect vitamin D levels. Efavirenz (Sustiva and in Atripla) and AZT (Retrovir/zidovudine, also in Combivir and Trizivir) have been linked to vitamin D deficiency.

Protease inhibitors (PIs), on the other hand, particularly darunavir (Prezista), have been associated with higher levels of vitamin D. Hal Huff, ND, head supervisor of the Naturopathic HIV/AIDS Clinic at the Sherbourne Health Centre in Toronto, is involved in the Canadian HIV Vascular Study, which is looking at the relationships between anti-HIV drugs, cardiovascular disease and metabolic problems. In the study, he says, "participants with the highest vitamin D status were more likely to be on PI-based ART rather than on a non-nuke such as efavirenz."

The study did not find a connection between efavirenz and low vitamin D levels; in fact, Dr. Huff says that vitamin D levels in the efavirenz group were relatively high, even in comparison with the general Canadian population. This

Even with supplements, it may not be easy to get vitamin D blood levels where they need to be.

would make it difficult to see a link between choice of anti-HIV drug and vitamin D levels.

Certain other medications that people with HIV commonly take may also affect vitamin D levels, including:

- the antibiotic rifampin (used to treat tuberculosis)
- the antifungal drugs clotrimazole and ketoconazole
- anti-inflammatory drugs such as corticosteroids
- the anti-seizure drugs phenobarbital, carbamazepine and phenytoin
- the anti-cancer drug Taxol and related compounds
- the herb St. John's wort and its extracts, hypericin and hyperforin

If you are taking any of these drugs or herbs, talk to your doctor about vitamin D.

D-MYSTIFYING

Over the past few years, there have been reports linking vitamin D deficiency to various health conditions. In HIV-negative people, low levels of vitamin D have been linked to some types of cancer—most notably colon cancer, but possibly also prostate and breast cancers. In HIV-positive people, type 2

diabetes and cardiovascular diseases, including heart attack and stroke, have been linked to low levels of the vitamin.

Dr. Huff and the other researchers with the Canadian HIV Vascular Study did not find a link between low vitamin D status and thickness of the carotid artery in the neck—a sign of cardiovascular disease—though this might have been because the group had relatively high levels of the vitamin.

They did note a possible link with high blood pressure; however, this does not mean that low vitamin D levels cause high blood pressure. "In our study, as in others, individuals with higher vitamin D status are less likely to be overweight," says Dr. Huff. "And, of course, being overweight increases the risk of elevated blood pressure."

Dr. Huff's comments highlight a weakness with much of the current research into vitamin D. The studies so far have shown a link between two factors, such as low vitamin D levels and cancer, but they cannot prove that low levels cause cancer. More rigorous studies are needed to prove a cause-and-effect relationship, and researchers are undertaking such studies to provide firm evidence.

Finally, Dr. Huff adds that the results of the study may not apply to everyone: "It is important to keep in mind that our study population was composed predominantly of white middle-aged HIV-positive men. For instance, they do not speak to the potential problem of vitamin D deficiency in HIV infection among women, Aboriginal

[people], persons with dark skin or the elderly.”

There is one area where experts are confident that vitamin D plays a role: bone health. A lack of the vitamin can result in soft bones (osteomalacia) and brittle bones (osteoporosis). Also, several studies have shown that elderly people who take vitamin D plus calcium have stronger bones and fewer broken bones. Vitamin D is needed by the body to properly use calcium, so the two micronutrients should be taken together (they are often sold in a combined pill).

ENOUGH OF THE GOOD STUFF

For people with HIV, who often have bone problems, the role of vitamin D in bone health is reason enough to be aware of their vitamin D status. The anti-HIV drug tenofovir (Truvada, also in Atripla and Complera) has been linked to thinner bones, so people taking that drug have an additional reason to pay attention to vitamin D. All people with HIV should consider talking with their doctors about vitamin D and the possibility of having their blood levels checked. People with certain other health conditions, including osteopenia or osteoporosis, can often have the cost of a vitamin D blood test covered by provincial and territorial healthcare programs.

If vitamin D is important, and it seems that many people don't get enough, where can they get more? There are three sources of vitamin D: sunlight, food and supplements.

Sunlight – Many factors affect skin production of vitamin D, making it difficult to provide general guidelines. For example, skin colour affects the time needed to make adequate quantities of the vitamin. (Dark-skinned people require between three and five times as much sun exposure to make the same amount of vitamin D as light-skinned people.) Also, many people wear sunscreen to help lower the risk of skin cancer. Moreover, exposure to enough sun is unlikely for much of the Canadian winter. HIV and HIV treatment can also slow or reverse vitamin D production. For all of these reasons, people should look to other sources.

Food – Natural food sources of this vitamin are few: dairy foods (especially certain cheeses, and milk, which by law is fortified with vitamin D), fortified soy and rice milks, orange juice, margarine and certain fatty fish, including salmon, tuna and mackerel. A number of other foods, including cereals, are also fortified with vitamin D.

The recommended daily intake for HIV-negative people between the ages of 9 and 70 is 600 IU. To achieve these amounts naturally, *Eating Well with Canada's Food Guide* recommends that all Canadians over the age of two consume 500 mL (two cups) of fortified milk or soy beverages every day. The American Endocrine Society suggests that people with certain medical conditions, including HIV, should have two to three times that amount (see How much

How much D for people with HIV?

- HIV-positive adults (19 to 70 years): at least 1,200 to 1,800 IU/day for healthy bones, maybe more to achieve other possible health benefits
- HIV-positive older adults (70+ years): at least 1,600 to 2,400 IU/day
- Adults should not take more than 4,000 IU/day without letting their doctor know

The American Endocrine Society, 2011

D for people with HIV?). That would mean four to six cups of fortified beverage a day!

Supplements – The most reliable way to get your vitamin D is through a supplement, and vitamin D₃ is the form of vitamin to look for on supplement labels. Vitamin D₃ is available as a pill and also in a liquid formulation. At the Sherbourne Health Centre's HIV clinic, the usual recommended intake is 2,000 IU per day. “We err on the side of providing more than what might be necessary,” Dr. Huff says. “Certainly, supplementation is most important October through April, particularly among persons with dark skin, a higher BMI, and in those who avoid summer sun exposure.”

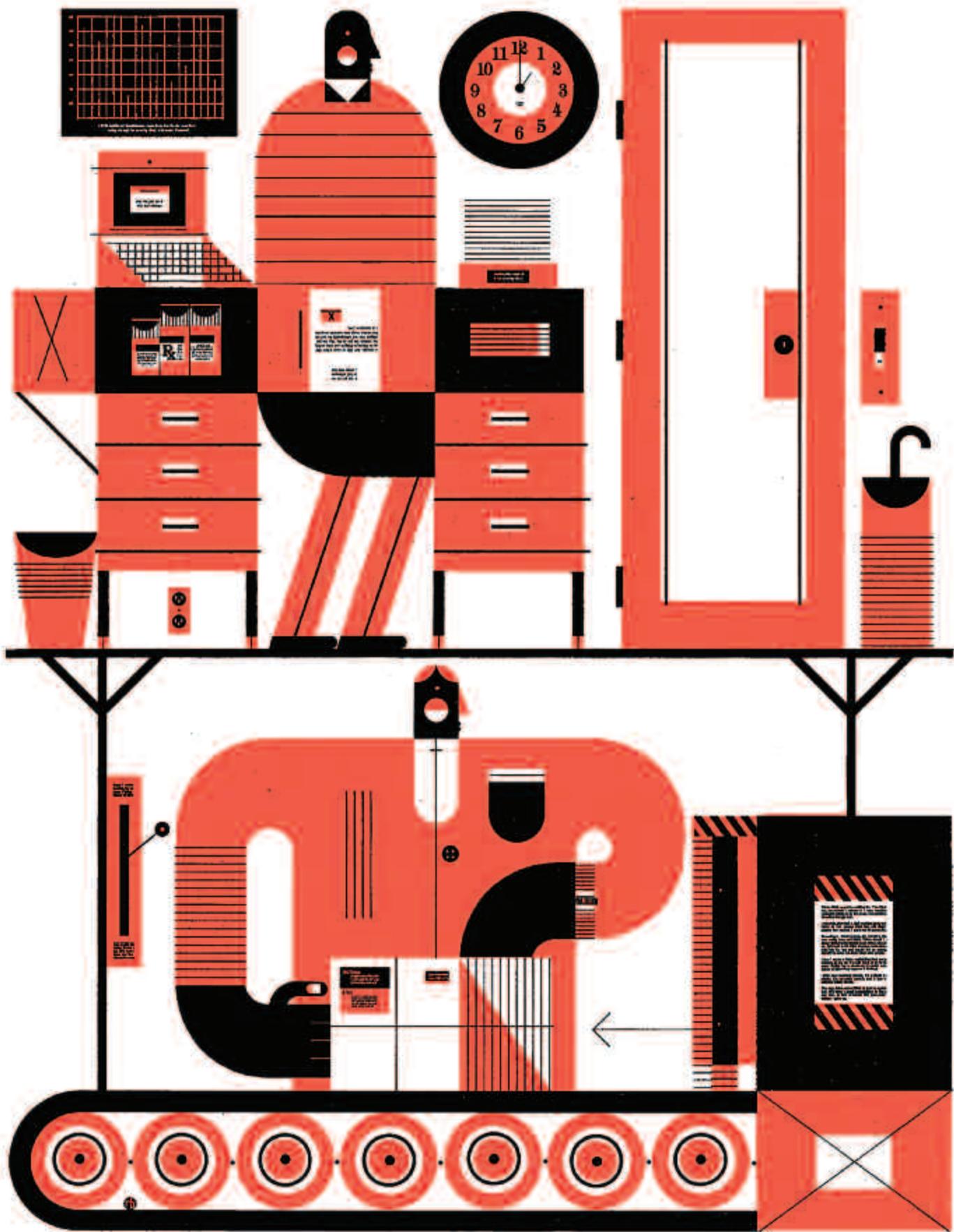
Even with supplements, it might not be easy to get vitamin D blood levels as high as they need to be. It may require high doses, such as 4,000 IU per day, taken for months to raise levels. Researchers are studying the effect of very high doses, such as 50,000 IU twice a week, over short periods. Early results are promising, with blood levels of the vitamin rising in the majority of people in some studies. More importantly, the doses seem safe and do not affect viral load or CD4 counts. Other trials are planned or underway with the goal of finding a safe and effective dose for HIV-positive people.

While taking a vitamin D supplement should be safe for most people, individuals with certain conditions that cause the immune system to become overly active and produce excess active vitamin D should only supplement under a doctor's supervision. These conditions include tuberculosis, chronic fungal infections and lymphoma.

It remains to be seen whether vitamin D will live up to all the hype, but its role in bone health is reason enough for us all to pay attention to our intake. Evidence suggests that taking a daily multivitamin and mineral supplement is probably not enough to ensure that people with HIV are getting enough vitamin D. A specific supplement of vitamin D₃ is likely a good thing, and it comes with the added bonus of providing an excuse for not heading out into the cold Canadian winter. +

For more information about vitamin D, check out *TreatmentUpdate 185* and *A Practical Guide to Nutrition*, both available online at www.catie.ca or by calling 1.800.263.1638.

R. Paul Kerston's work at the Positive Living Society of BC includes treatment outreach. When he's not spreading the word on treatment, he can be found trotting the globe (40 countries and counting) and indulging in his longtime passion for theatre performance.



A HARD DAY'S WORK

Working while living with HIV presents its own challenges but, for those who can, it pays off—and not just in the bank account.

BY DIANE PETERS

ILLUSTRATIONS BY RAYMOND BIESINGER

It was 1998 and Ian Nelson's friends were dying. HIV positive for 12 years, he was feeling terrible on a dual therapy of AZT and ddI. "My mind was mush," recalls the now 51-year-old Vancouverite. His management job for Canada Post involved a 6:30 am start time and intensive problem solving, and the stress and workload were becoming unmanageable. Feeling depressed and convinced that his health was about to seriously falter, Nelson went on disability leave.

At first, he relished spending long days at the beach. But, within months, boredom and depression set in, and he began taking acid and mushrooms, then progressively harder drugs. By 2000 he was addicted to crystal meth and living on government assistance, relying on food banks, yard sales and dumpster diving to eat.

In 2004, he suffered congestive heart failure. After being released from the hospital, Nelson came to the realization

that he wanted to live. While doing outpatient physiotherapy, he began attending 12-step meetings and doing volunteer work with the AIDS service organization (ASO) Positive Living BC (formerly BC Persons With AIDS Society). When someone suggested he apply for a part-time job there the following year, his confidence was still so shot that he nearly didn't go for it. But he found the courage, landed the job and a couple of years later was hired on full time as the ASO's reception services coordinator.

Now, Nelson hits the gym three times a week, goes to the beach when he can and recently took his first holiday in eight years, to Oregon. He's also recently restarted a daily regimen of anti-HIV medications. He thrives on the routine of his job, has built up his confidence and enjoys the positive energy of his co-workers and volunteers. "I'm so happy that I've met all these wonderful people. They would not be in my daily life if I was at home."

WORK OF ART

Ever since the late 1990s, when the advent of antiretroviral therapy (or ART) offered a means to effectively control the virus, people living with HIV have struggled with incorporating work into their lives. While HIV is no longer a one-way exit out of the workforce, staying employed has its complications. Many people are still simply not well enough to work, while others, who feel good and want a job, face barriers.

Even for those who feel good, that feeling of well-being may come and go. Living with HIV comes with periods of poor health when working is difficult or impossible, episodes that can have a serious impact on people's health and income stability, as was Nelson's case.

Of the estimated 65,000 people living with HIV in Canada, no one knows precisely how many are in the workforce. Sergio Rueda, director of health research initiatives at the Ontario HIV Treatment Network (OHTN), led a survey of 2,000 people with HIV in Ontario and found that 40 percent of the men and 48 percent of the women were employed. Rueda also analyzed data from a group of 1,525 HIV-positive men in the United States: 41 percent of them were continuously employed over 10 years, 25 percent were unemployed and 20 percent worked on and off.

Illness, fatigue and side effects such as nausea and cognitive problems make a 40-hour work week difficult or

"I want to work at an HIV organization, where my **co-workers** will understand the reason I might have several doctors' appointments in one month."

Hot topics in HIV & work

Newcomers – Many HIV-positive immigrants face unique challenges, including language and cultural barriers and a lack of understanding of how to navigate the Canadian job market—on top of the day-to-day struggles of living with HIV.

Retirement – Many HIV-positive people contemplating retirement face a big question about how to access drug and health benefits after retiring. As more and more people with HIV move toward retirement, this issue will become even bigger.

Policy changes – Finally, employers need help to understand the implications of new and upcoming policies designed to help protect people with disabilities in the workforce. In 2010, Canada ratified the Convention on the Rights of Persons with Disabilities (CRPD). As well, Ontario is in the process of implementing the Accessibility for Ontarians with Disabilities Act (AODA) and other provinces are looking at similar laws. Holding governments and employers accountable for putting these standards into action will help people with HIV enter and stay in the workforce.

impossible for some people with HIV. Others who feel well find that working full time makes keeping numerous doctors' appointments a logistical challenge. Depression, particularly for newly diagnosed people, can hold someone back from pursuing work or the education that leads to a career. People new to Canada may be juggling health concerns along with learning English and dealing with government paperwork.

Rules for getting and staying on income and medical support programs can also hold people back from taking a job. Many people feel programs such as the Canada Pension Plan's Disability Benefits Program or private long-term disability plans are not flexible enough to take into account episodic bouts of illness and wellness. "Often you're either in, or you're out," says Don Phaneuf, director of employment and volunteer services for the AIDS Committee of Toronto (ACT).

Figuring out if it's worth it to stop a program and begin work, particularly part time, can be complex. ASOs spend a great deal of time helping clients decipher the rules. Programs usually reduce benefits, potentially also medical benefits, when other income is made. "There's little incentive for people to work under these programs," Phaneuf says. The result: Many stay unemployed (sometimes giving back through volunteer work) or find work for which they can get paid under the table.



WORK IT OUT

Theresie Nuwimana is still exploring what it's like to work and live with HIV in Canada. The 43-year-old knew of her status when she emigrated from Rwanda to Toronto in 2005. When she first arrived, she focused on learning English and then enrolled in a program to train to be a personal support worker. Once she began doing home care visits, however, she found commuting and working long hours to be too much. "I was exhausted by the end of the day. It wasn't good for my health." So Nuwimana went back to school and graduated this past autumn from a counselling and advocacy program at George Brown College.

However, her last placement at a women's shelter also proved a challenge. Since she sometimes needed to start late to work around doctors' appointments, she felt it wise to disclose her status to her supervisor, who was understanding and supportive. She did not want to disclose to any other staff, though it was hard to avoid their curiosity. Because Nuwimana worked shifts, she was constantly teamed with new co-workers, some who didn't necessarily understand her need to work flexible hours or why she had yet another appointment. "I want to work in a smaller place," she says. "What I really want to do is work in an HIV organization, where my co-workers will understand the reason I might have several doctors' appointments in one month."

No one starts a job knowing everything about it, and discovering what you need once you're on the job is not uncommon. "It's important for people to understand their tolerance for a bit of uncertainty," says Melissa Popiel, coordinator of HIV and Episodic Disabilities Initiatives for the Canadian Working Group on HIV and Rehabilitation (CWGHR). "For example, you may not know in advance what your benefits plan will be like, or what the workplace culture will be."

And not all jobs suit people with HIV. Many tend to avoid high-stress jobs and physical work that involves heavy lifting. Shift work can wreak havoc on sleep and med schedules. Those who experience cognitive side effects from their meds also have to take that into account when looking for work.

As well, an HIV-positive person may need the workplace to be accommodating in certain ways. "[People with HIV] should know that they have a right to be treated without discrimination in the workplace. That's one thing," says Renée Lang, staff lawyer at the HIV & AIDS Legal Clinic Ontario (HALCO), "but you also have a right to accommodation because of your disability." Except for jobs under federal law (such as working for the Canadian government), the specifics of those rights fall under provincial labour standards and human rights legislation. "Most of the time, what clients are asking for is quite reasonable," Lang says—access to a private bathroom, a place to store meds or a quiet room for naps or downtime. Most commonly, people are requesting flexible hours, like starting an hour later some days.

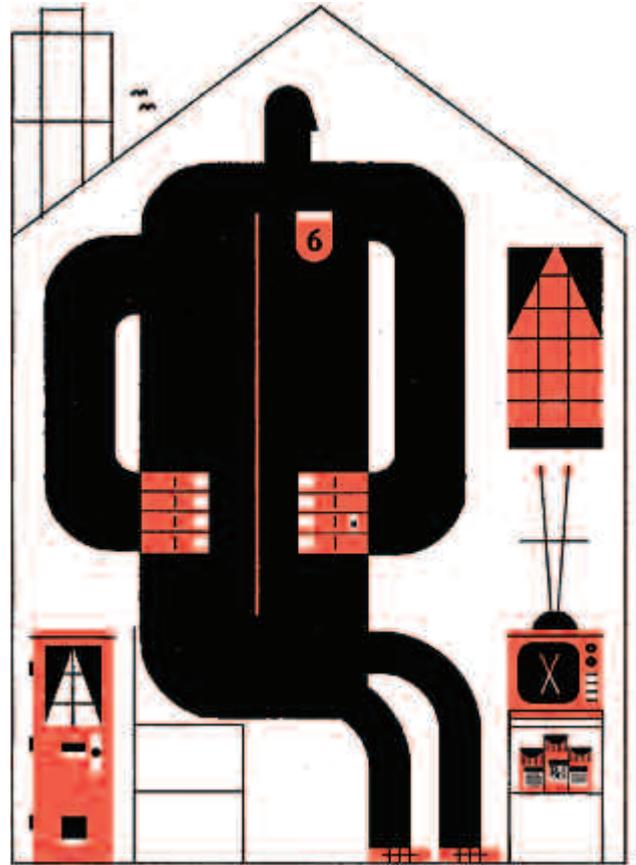
"Workplace accommodation is a process," Popiel says. People taking on a new job should be sure they can do the core tasks—the accommodation would make small changes to the work environment so the job is accessible and not

Discrimination on the job?

If you're being discriminated against on the job, or if you get fired—you suspect—because of your HIV status, there are ways to seek justice. If you've been at a job for a few years, it might be worthwhile to pursue fair severance through the courts with the help of a lawyer. Or, if you haven't worked at a job for long, or you've experienced serious discrimination, you might seek damages through your province's human rights commission. If you were seriously wronged, you could get an apology or even a monetary settlement.

But be forewarned: Seeking justice is not an easy process. It takes time and your previous employer might say some pretty nasty, even untrue, things. "If you put in a complaint," says HALCO's Renée Lang, "you're going to hear stuff back that you don't want to hear."

“My job gives me something to distract me. I feel good about myself rather than **staying at home** and worrying about my illness.”



unhealthy for someone with a disability. While employees have the right to these changes, employers have rights too, and the law protects companies from making accommodations that would affect the success of their businesses.

Employees should be prepared to discuss options with their employer and know that if there are a number of appropriate options, employers can choose the one that best fits the needs of the organization. “If an accommodation isn’t working well, employees should talk with their employer immediately, so that the problem doesn’t become a performance issue,” Popiel advises.

To set up the right accommodation, people with HIV have to speak up at work. However, that does not necessarily mean disclosing their HIV status. In fact, most jobs in Canada do not require disclosure, and privacy and human rights law protects your right to not disclose.

While many worry that ill treatment of HIV-positive people in workplaces is common, Lang says that, in fact, such cases rarely come up. “Frankly, we see more concerns about stigma and discrimination than we see it playing out.” (Discrimination on the job? on page 19 has more information about your options if you feel you are facing discrimination because of your HIV status.)

The only job in Canada that HIV-positive people are not permitted to do is that of emergency medical technician (EMT,

also known as a paramedic). Physicians must disclose their status to their professional college but not to their employer or patients, and they can safely do their jobs thanks to universal precautions. (This was tested within the legal system after a Quebec pediatric surgeon’s HIV status was revealed following her death in 2003. The Canadian Medical Association stated that she had no obligation to disclose.)

People with HIV must reveal their condition to an employer’s health insurance company but even that is private. For instance, if human resources asks you to fill out a medical form and hand it to them, you can request to send it to the insurer directly. Lang says it’s important to never lie on questionnaires that ask if you’re taking medication or have underlying health issues. Just tick off “yes,” and use the comment section to say that your condition will not affect your work.

To get accommodation, a person must provide a doctor’s note, but that can state that you suffer from fatigue or nausea without revealing the underlying cause. By law, your employer can’t probe for more details.

Working freelance is an option that avoids dealing with an employer and a workplace, and it seems like the perfect job: work from home while running your own business. No office politics to stress you out, no rigid start time to interfere with sleep and meds, and no commute. Many people with HIV

thrive as freelancers and find it's the only way they can work and stay well. Others find challenges in this career path.

Such as John Smith. For years he was a successful self-employed retail consultant. But the stress of his HIV diagnosis in 2010 and feeling unwell made it impossible to work for a few months. Being at home alone, letting his business slide, did not help: "It made me reclusive and isolated." Freelancers can lack the kind of social support those with traditional jobs often find at work. They don't have access to company benefits plans. And the worry that comes with business fluctuating doesn't help stress levels.

Smith soon got his health back on track and worked with Employment Action in Toronto to rebuild his resumé and find a full-time job. Going out every day, seeing other people and keeping busy has done a lot for him. "It gives me something to distract me," he says. "I feel good about myself rather than staying at home and worrying about my illness."

POSITIVE PAYBACK

For people with HIV who do manage to get around the challenges and either continue working or return to work, the value is huge. In a recent survey study, OHTN's Rueda looked at 18 previous studies charting workplace status and health. These reports revealed that working is not just associated with good health—since, of course, healthier people are more likely to work—but also that "these findings suggest causation," Rueda says. "Employment leads to better health." He also discovered in this study that losing a job can put a dent in your health, but going back to work later on can bump it back up again.

A paying job gives you money, which allows you to eat well, find a good home and, like Ian Nelson, enjoy healthful perks like gym memberships and vacations. In a 2011 survey of people with HIV in Ontario led by Rueda, people said the most important thing a job gave them was a sense of identity. "Work lets you be defined by what you do, not just by your illness," says André Samson, professor in the department of counselling at the University of Ottawa. "Working is the normal experience during adult life. It is our main activity, it's how we express ourselves and are a part of society." As well, jobs can offer a social network to lean on when times are tough.

To capitalize on these benefits, some organizations are trying to remove return-to-work obstacles at the government and workplace levels. And not just for people with HIV: Arthritis, mental illness and some cancers—conditions that affect millions of Canadians—are also episodic disabilities that can affect a person's ability to work full time. Organizations such as CWGHR are working with governments to change social support rules and educating workplaces about discrimination, accommodation and episodic illnesses. Their work is having an effect. For instance, when Popiel began speaking to human resources professionals four years ago, only a few had heard of the term "episodic disabilities." These days half the room knows the term.

Services for HIV-positive people seeking work are also growing. People in Toronto can turn to ACT's Employment

Action to talk about career issues, spruce up their resumes and find jobs. Across Canada, people with HIV and anyone with a chronic illness can access CWGHR's newly launched Episodic Disabilities Employment Network (EDEN), a web-based peer support portal.

These changes are not yet enough to get every HIV-positive person who wants a job out there working for a regular paycheque. But they're a start toward enabling people to build a future for themselves and showing the work world that HIV does not have to stop someone from contributing. People with HIV or other episodic disabilities have both a right to work and a great deal to offer to our society and economy. +

Diane Peters is a Toronto-based freelance writer and teacher. She writes about health, business, parenting and other issues. This article was researched with funding assistance from the Canadian Institutes of Health Research (CIHR).

Work tools

The following resources provide information or support on employment issues for people with HIV. To find support in your area, visit www.aso411.ca for an AIDS service organization close to you. Or call CATIE at 1.800.263.1638 and we can direct you to a local organization.

Episodic Disabilities Employment Network (EDEN)
www.edencanada.ca

Canadian Working Group on HIV and Rehabilitation (CWGHR)
www.hivandrehab.ca
(check out Information for People Living with HIV)

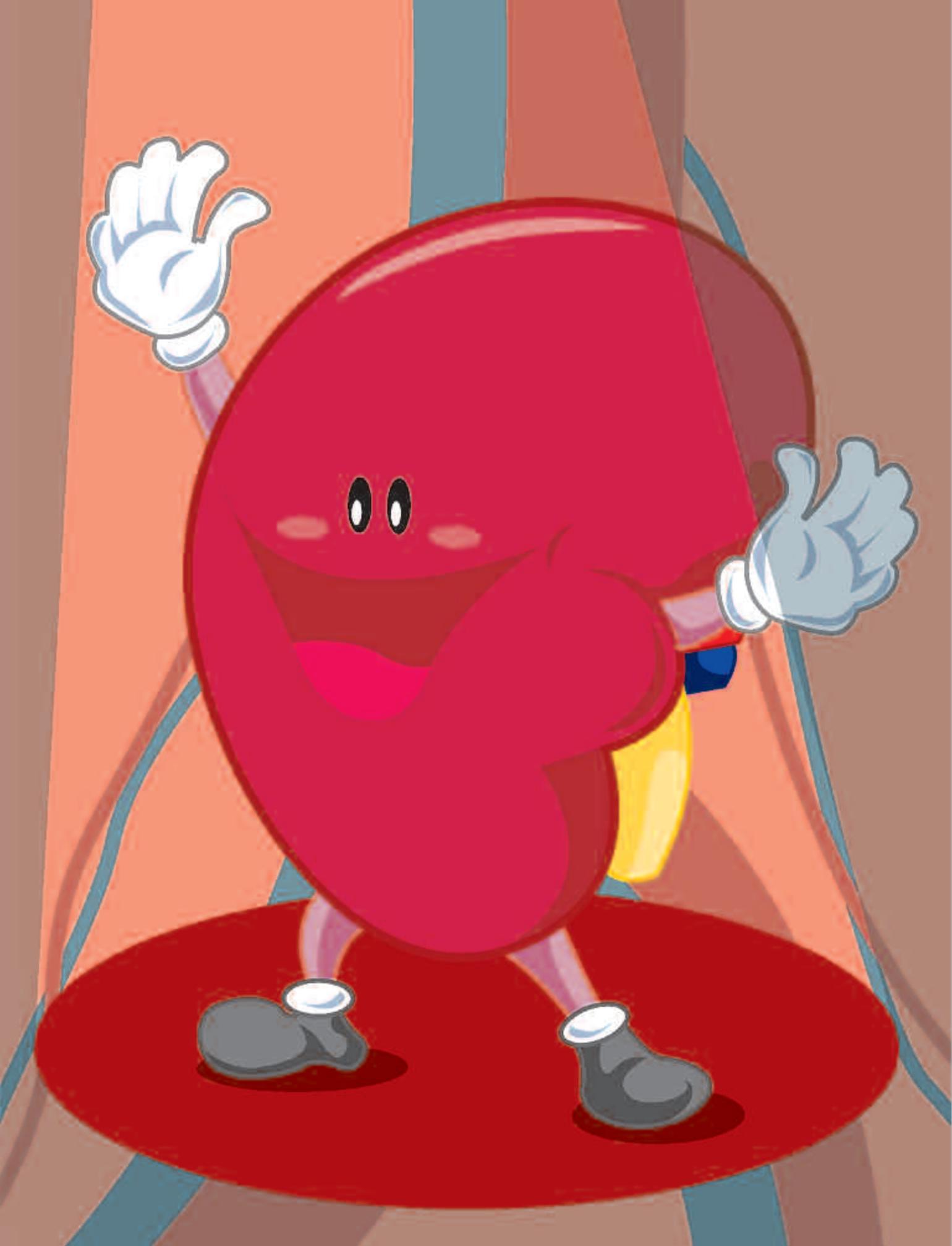
Resources from Interagency Coalition on AIDS and Development (ICAD)
www.icad-cisd.com
(search for the term "disability")

Fact sheets on HIV and work from AIDS Calgary
www.aidscalgary.org
(on the Publications page)

Employment Action (a program of the AIDS Committee of Toronto)
employmentaction.crescan.com
(serves the Greater Toronto Area only, but check out the Working and HIV/AIDS section)

Canadian HIV/AIDS Legal Network
www.aidslaw.ca

HIV & AIDS Legal Clinic Ontario (HALCO)
www.halco.org
(serves Ontario only)



Kidneys Take Centre Stage

Maggie Atkinson shines a much-needed spotlight on the latest research on HIV and kidney health and updates us on her efforts to keep her pair of these unassuming stars performing smoothly.

Back in the early 2000s I faced some kidney problems, so, in my usual determined way, I set out to learn more about the kidneys and what I could do to protect them. I wrote about that experience in “Here’s Lookin’ at You, Kidneys” in the Fall/Winter 2005 issue of this magazine. During the past six years, much has changed for me and in our understanding of HIV and the kidneys, so it’s time for an update.

The face of kidney disease in people with HIV is changing. Thanks to antiretroviral therapy (ART), we are surviving longer but we are also experiencing higher-than-normal rates of high blood pressure, diabetes and high cholesterol, which can all contribute to the development of kidney disease. People with HIV also have other risk factors that make us more susceptible: HIV can infect kidney cells and cause disease. Also, some medications taken by people with HIV (including certain antiretrovirals) can harm the kidneys.

Given all these factors, perhaps it shouldn’t be surprising that about one-third of people with HIV in Canada have some kidney impairment. Because kidney function declines

with age, this number will likely increase as more of us live longer. The good news is that we can do something about certain risk factors. But before we look at those risk factors and what we can do about them, let’s take a moment to talk about the kidneys and what can go wrong with them.

DAMAGED FILTERS

Many people know that the kidneys—two bean-shaped organs located on either side of your spine about midway up your back—filter the blood and expel waste from our bodies, in the form of urine. But they do a lot more than that. The kidneys have four main functions:

- 1 They remove extra fluid from the blood.
- 2 They balance minerals in the blood.
- 3 They remove waste products.
- 4 They produce essential hormones that help us make red blood cells, regulate blood pressure and maintain calcium for our bones.

My KIDNEY STORY

When I started taking tenofovir, my kidney function (as measured by my GFR, or glomerular filtration rate) remained stable. However, over the next couple of years, my creatinine shot up and correspondingly my GFR declined from 90 (normal) to below 60, indicating chronic kidney disease. I felt fine but I got a call from my doctor who told me that there was protein in my urine, which meant kidney damage. My only risk factor was tenofovir. (I know now that having elevated cholesterol from taking anti-HIV meds was probably contributing. Also, I was on dual protease inhibitors, which may have boosted my blood levels of tenofovir and increased its toxicity.)

With kidney disease, it is usually the kidneys' filtering units—the nephrons, which eliminate waste and excess fluid—that are damaged. When this happens, dangerous levels of fluid and waste can accumulate over time in the body. Swollen hands and feet, fatigue, urinating more or less often than usual and cloudy or dark-coloured urine are some of the signals of possible problems, although there are often no obvious signs at first.

Kidney disease can be either acute or chronic. People with HIV are at higher risk for both. If we've had one, then we're more prone to develop the other.

When a person's kidney function declines quickly, this is called *acute kidney injury*. It can result from poisoning, infection or injury. A recent US study showed that in most cases of acute inflammation of the nephrons in people with HIV, drugs were to blame—most commonly, nonsteroidal anti-inflammatory drugs (such as ibuprofen) and the antibiotic combo Septra/Bactrim. In only three out of the 21 cases of acute kidney injury due to medications, antiretrovirals were the culprit.

Chronic kidney disease involves a more gradual loss of kidney function and is defined as kidney damage that lasts for three months or more. The two most common causes of chronic kidney disease are diabetes and high blood pressure. Between two and 10 percent of people with HIV have chronic kidney disease.

When left untreated, kidney disease can be serious, even fatal, due to imbalances in blood levels of minerals and hormones or the build-up of fluid in the body. In extreme cases, dialysis or organ transplant is needed to replace the function that the kidneys normally perform. (People with HIV can now get kidney transplants in British Columbia, Ontario and Quebec.) Both acute and chronic kidney disease are associated with greater risk for cardiovascular disease and death among people with HIV than among HIV-negative people. Chronic kidney disease has also been linked to bone disease and cognitive impairment.

YELLOW LIGHTS

Who runs a higher risk of chronic kidney disease? People with HIV who can check off one or more of the following are at greater risk:

A low CD4 count or high viral load – People with HIV whose CD4 count is lower than 200 or whose viral load is greater than 4,000 are at increased risk.

African ancestry – Kidney failure due to HIV infection in the kidney cells (HIV-associated nephropathy, or HIVAN) is more common in

people of African descent because of a genetic predisposition (though it is not more common in people of Ethiopian descent).

Hepatitis co-infection – Hepatitis can damage the kidneys as well as the liver.

Alcohol and drugs – Consuming large amounts of alcohol or street drugs, such as cocaine, heroin and amphetamines, can damage the kidneys.

High cholesterol, high blood pressure and diabetes – People on ART who have high cholesterol, high blood pressure or diabetes have a higher chance of seeing their kidney function decline.

Older age – Every year after the age of 30, the average person loses one percent of their kidney function. Since accelerated aging has been seen in people with HIV, we may be even more susceptible to chronic kidney disease as we age.

Inflammation – People with HIV, even those with an undetectable viral load, have higher markers of inflammation in their blood than HIV-negative people. Inflammation is associated with a greater risk of both cardiovascular and kidney

Many medications, including ibuprofen and Aspirin, can damage the kidneys and should be used with caution.

Worried, I met with a nephrologist and my HIV specialist, who recommended that I stop taking Septra/ Bactrim (which I was on to prevent PCP), because it can be nephrotoxic, and switch from tenofovir to raltegravir (Isentress). I hated changing drugs because I have a history of side effects and allergic reactions, but the tenofovir had to go. Within a month, my GFR had risen to 65—a more reassuring number—and it continued to rise, although it has never returned to normal.

In addition to switching meds, I also began to follow the Pritikin program of diet and exercise, which is known to reduce inflammation. Similar to the DASH diet, the program recommends eating fruits, vegetables, legumes, whole grains, seafood and lean chicken, and avoiding added fats, salt and sugar. It also stresses the benefits of exercise on a daily basis. These lifestyle changes lowered my blood pressure and cholesterol and made me feel 15 years younger! I continue to try to follow this program as much as possible to avoid disease (including kidney disease), prevent accelerated aging associated with HIV and have more energy.

disease. Aging and excess body fat can also cause chronic low-level inflammation.

Antiretrovirals – The antiretrovirals tenofovir (Viread, also in Truvada, Atripla and Complera), atazanavir (Reyataz) and indinavir (Crixivan) can cause kidney damage. Tenofovir can have acute and chronic effects on the kidneys. Fortunately, less than one percent of people who take tenofovir experience serious kidney injury. Atazanavir can cause kidney stones and interstitial nephritis, a condition in which the spaces between the nephrons swell. One study found that atazanavir was associated with a 22 percent increase in the incidence of chronic kidney disease per year of exposure; when taken with tenofovir, that rose to 41 percent. Indinavir, not used as much anymore, can cause crystals, kidney stones and interstitial nephritis to develop.

Transplant meds – Medications that are increasingly being used not only after a transplant but also to treat inflammation can be a risk factor as well.

Because most people have no symptoms in the early stages of

chronic kidney disease, regular testing is critical. Your doctor may order one or more of the following simple tests:

- a urine test to look for protein in the urine, which can be a sign of kidney damage. Levels of protein, or albumin, that are higher than normal for three months or more indicate chronic kidney disease.
- a blood test to measure creatinine, a waste product from the muscles that shows up in the blood when the kidneys aren't able to get rid of it. The result from this test is used to estimate your GFR (glomerular filtration rate), which tells you and your doctor how well your kidneys are doing their job (see Getting to Know GFR, below).

Fortunately, these tests are usually part of the standard set that your doctor orders during checkups and physical exams.

KIDNEY CARE

Unfortunately, in many cases, kidney disease cannot be completely reversed but its progress can often be slowed and the symptoms managed. Starting new meds, adjusting the dosage of drugs you're already taking and making lifestyle changes can all help. (Read My Kidney Story to see how I did it.)

For people with HIV infection in the kidneys (sometimes called HIV-associated nephropathy, or HIVAN), we now know that it's important to start ART regardless of CD4 count or viral load. We also know that it's important to stay on treatment: In a large international study, people who interrupted their ART had a 50 percent higher risk of developing chronic

kidney disease than people who continued taking the medications. Other meds, such as corticosteroids (which reduce inflammation) and angiotensin-converting enzyme (ACE) inhibitors or angiotensin receptor blockers (ARBs), which lower blood pressure, can also help protect kidneys damaged by certain types of kidney disease.

At the same time, as Jeff Kapler, pharmacist at the Southern Alberta Clinic for HIV/AIDS in Calgary, points out, many medications—including ibuprofen, Aspirin and other over-the-counter drugs—can damage the kidneys and should be used with caution.

Sometimes changes to the dosage of medications are needed to protect the kidneys. If you have signs of chronic disease (your GFR is lower than 60), your doctor will likely lower the dosages of certain meds, such as Septra/Bactrim,

Getting to Know GFR

The GFR estimates how much fluid is passing through the nephrons and measures your kidney health.

A GFR (ml/min) of	indicates...
90+	normal kidney function
60–89	early kidney disease
<60	chronic kidney disease
<15	severely impaired kidney function—dialysis or a kidney transplant is needed

Atripla, atazanavir, maraviroc (Celsentri), lopinavir/ritonavir (Kaletra), and nucleoside drugs with the exception of abacavir (Ziagen).

However, medications are just one part of caring for your kidneys—a holistic approach is crucial. That involves looking at how other parts of your life can impact your kidney health. For people with chronic kidney disease, an exercise program that combines cardiovascular exercise and resistance training has a long list of benefits: It can reduce inflammation and improve cardiovascular function, strength, endurance and quality of life. Not to mention that it can help prevent type 2 diabetes, reduce high blood pressure and improve your cholesterol. Be sure to talk to your doctor before you start an exercise program.

What we eat affects our kidney health, too. The DASH (Dietary Approaches to Stop Hypertension) diet—which is low in salt and high in fruits, vegetables, legumes and nuts, whole grains and low-fat dairy products—has been shown to lower blood pressure without medication. A recent study found that a DASH-style diet is much better than the Western diet (which usually includes more red meat, sweets, salt and saturated fats) for kidney function. A dietician—ideally

one who specializes in diets for people with kidney problems—can provide more advice.

Many people with HIV take vitamins or supplements. These can have benefits, but be aware that some herbs can affect kidney function or interact with prescription medicines, including anti-HIV drugs, and over-the-counter products. Interactions can change the medication's effectiveness or make side effects of the drugs worse. Be sure to let your doctor know about all the herbs, supplements and other complementary therapies you are taking, especially if you have more significant kidney impairment, or if your GFR is below 30.

Being kind to your kidneys means balancing the right mix of meds, a kidney-friendly diet and an active life. Pharmacist Jeff Kapler puts it well: “The different parts of our bodies are so interconnected, and the kidneys are kind of at the centre of things. The management of your overall health is critical.” +

Maggie Atkinson is an AIDS activist and lawyer. She is the former co-chair of AIDS ACTION NOW!, the founding chair of Voices of Positive Women in Toronto, and a recipient of the Order of Ontario. She has been living with HIV for more than 25 years.

ASK THE EXPERTS

We asked a kidney specialist (a nephrologist), a pharmacist and a naturopath to share their tips and insights on how people with HIV can be kind to their kidneys.



ALIREZA ZAHIRIEH, MD

Nephrologist, HIV Renal Disease Clinic
Sunnybrook Health Sciences Centre
Toronto

The prevention and treatment of kidney disease go hand in hand. A healthy lifestyle is essential for both. That means regular exercise, eating a well-balanced diet according to *Canada's Food Guide*, and cutting back on alcohol, tobacco and street drugs. People with HIV should also see their physicians and get screened regularly for kidney disease.

Kidney disease appears to be more common among people living with HIV than in the general population. Many of my patients have kidney disease that is not related to their HIV infection but rather to traditional risk

factors—such as diabetes, high cholesterol, hypertension and smoking—which are all more common among people with HIV. To manage kidney disease, one should manage the risk factors as much as possible. This includes controlling HIV with anti-retroviral therapy.

Kidney disease has much in common with cardiovascular disease. In general, what's good for the heart is good for the kidneys. The chronic inflammation observed in some individuals with HIV infection puts them at risk for atherosclerosis (hardening of the arteries) and thus at risk for heart attacks, strokes and chronic kidney disease. Fortunately, treating kidney disease also treats these other serious diseases.

When it comes to kidney disease, one must pay particular attention to drug-related kidney injury. Certain drugs are more likely to cause kidney injury, but almost any drug can cause an allergic reaction that affects the kidneys. To avoid injuring the kidneys, it is very important to ensure that medications are taken at appropriate doses. Also, when starting a new drug or changing the dose of a current drug, careful monitoring is often required. Certain over-the-counter medications, such as ibuprofen (Advil, Motrin) or high doses of Aspirin, may cause kidney disease in individuals at risk for this complication. Finally, drug interactions can cause potentially dangerous adverse effects; it is crucial that your healthcare providers know the names of all the medications you're taking, including over-the-counter products and supplements.

In summary, a healthy lifestyle, aggressive treatment of risk factors for chronic kidney disease (including HIV infection), careful use of medication and a well-balanced diet will help protect your kidneys.

JEFF KAPLER, BScPharm

HIV specialty pharmacist

Southern Alberta Clinic for HIV/AIDS

Calgary

Many meds can affect kidney health, including some antiretrovirals. Certain antibiotics and blood pressure meds, anti-inflammatories and street drugs can all cause kidney damage. It is important for people who are at higher risk for kidney disease to use over-the-counter medication with caution. If someone is on anti-HIV drugs and has borderline kidney function, ibuprofen can tip the scales and cause additive kidney damage. For fever or pain relief, acetaminophen (Tylenol) is a good alternative, unless a person has severe liver disease.

Like many drugs, tenofovir (Viread, also in Truvada, Atripla and Complera) is cleared from the body by the kidneys. There are cases of kidney damage among people taking tenofovir. Results from a French cohort study looking at tenofovir's contribution to kidney disease were presented

at the 2011 International AIDS Society conference in Rome. Of the roughly 2,700 participants on tenofovir, less than 5 percent developed chronic kidney disease. Of those who did develop chronic kidney disease, 90 percent already had reduced kidney function when they started taking tenofovir and they had other risk factors as well. If a patient is at considerable risk for kidney disease, I would recommend other options if available. However, tenofovir is not a drug to avoid in general, and especially if there are no other options for putting together an effective regimen.

Any medication that can cause crystals to form in the kidneys can harm the kidneys. There have been some reports of the protease inhibitor atazanavir (Reyataz) causing the formation of crystals and kidney stones, but much less so than indinavir (Crixivan), which has been associated with kidney stones in up to 13 percent of users. Indinavir is rarely used in Canada nowadays, but I recommend to my patients on atazanavir that they drink a minimum

of eight glasses of water a day, especially in the summer months.

Maintaining one's overall health—keeping cholesterol, blood sugar and blood pressure at optimal levels—is important for the kidneys.

AGNIESZKA MATUSIK, ND

Doctor of Naturopathic Medicine

Burnaby Heights Integrative

HealthCare

Burnaby, BC

It is important that people with HIV consume enough calories, protein, fat, water and other fluids, as well as antioxidants. Antioxidants protect the kidneys from nephrotoxic medications (medications that can be toxic to the kidneys) and from the harmful effects of HIV. Everyone should take a daily multivitamin and eat plenty of fruits and vegetables. A minimum of five servings of fruits and vegetables every day is optimal, including a variety of brightly coloured ones. Antioxidants clean up the free radicals created during the inflammatory response. Fish oils and omega-3 fatty acids have anti-inflammatory properties.

I prescribe antioxidants such as vitamin E, vitamin C, selenium and n-acetyl-cysteine (NAC), to help the body produce glutathione, an important antioxidant that can't be directly supplemented. Some botanical medicines or herbs can protect the kidneys and stimulate the immune system; several studies support the use of astragalus, curcumin (turmeric), alpha-lipoic acid, coenzyme Q₁₀ and spirulina. Curcumin is one of the best.

If someone develops kidney disease, their vitamin D levels should be tested and if they're too low, supplemented, because the kidneys are involved in making vitamin D. A person shouldn't take too much vitamin C because this can in some cases contribute to kidney stones.

It is important to talk to a health professional, like a naturopathic doctor, before taking any supplements. The dosage must be tailored to the individual and should take into consideration any other conditions they may have and other medications they may be taking. +

In general,
what's
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kidneys.

Fighting Spirit

Simon Thwaites first made headlines when the Canadian military fired him for being HIV positive. Almost two decades after winning his landmark case, the ex-sailor has found a new way to express himself and connect with others through painting.

BY JENNIFER MCPHEE



"Frustration," 2011

Halifax painter Simon Thwaites may be a warm, kind person with a natural gift for putting people at ease, but don't get the wrong idea. He's nobody's pushover: Pick a fight with him and the odds are against you.

Thwaites' most legendary battle began in 1989 when the Canadian Armed Forces (CAF) fired him for being HIV positive mere months before he was eligible for a medical pension. Before giving Thwaites his marching

orders, the navy yanked his security clearance, which meant he was assigned to menial tasks typically reserved for navy personnel who commit offences. "My friends in the military thought I had committed

some kind of heinous crime,” Thwaites says with a laugh. At one point, the CAF even placed him in isolation and required him to wash his own toilet and tub with bleach.

The navy estimated that Thwaites would die within three years, but he was still around to celebrate in 1994 when the Federal Court of Canada upheld his landmark human rights case, sending a clear message to employers not to discriminate against people with HIV.

Human rights lawyer Peter Engelmann, who acted for the Canadian Human Rights Commission throughout the case, says the medical evidence introduced during the hearing helped educate Canadian employers about HIV at a time rife with false fears and misconceptions about the disease.

Engelmann recalls that Thwaites was compassionate and calm despite everything he had been through: “He took up this fight, which was especially courageous in those days. He was determined to see it through.”

This past year, Thwaites, 49, began revisiting his journal entries from that tumultuous period and turning some of those emotionally charged memories into visual art. Back then, he titled his journal “Dead Man Talking” because the military was treating him as though he were already dead.

Even though the paintings inspired by journal entries from that period express red-hot anger toward the CAF, the images also reveal his determination to rise above his situation. His Salvador Dali-esque painting “Frustration” depicts a skeleton in chains kneeling in a graveyard on top of a pile of skulls with red ribbons on their foreheads. In the midst of this, a man standing on the skeleton’s back sprouts wings.

“The skulls are the people who have died before me... I am literally standing on their backs,” Thwaites explains. “The chains exist because I am trapped in that, yet there’s this individual in the middle trying to escape and be a person in life instead of just a skeleton or skull.”

Even Thwaites is surprised by the depth of his anger back then. “I didn’t realize at the time that I was going

through that process,” he says. “I’ve never been angry for having HIV. I was angry at the way I was treated... How you treat people who are sick or going through a challenge in their life, that’s totally within your control. Maybe I expect too much from people, but I think that the human race is better than that.”

The court awarded Thwaites more than \$160,000 in compensation, which amounted to roughly \$30,000 after lawyers’ fees and taxes (and the government clawed back even more later). He used the cash to put a down payment on a house and began to focus on creating art—something

“I have never been angry for having HIV. I was angry at the way I was treated.”

he’s excelled at since childhood. “My teachers made art fun,” he says. “Everything else you do in life is either right or wrong. But they instilled in me that art can never be wrong.”

Thwaites now enjoys the challenge of teaching himself new techniques and sees art as a way to connect and communicate with others. For this reason, his work reflects his own experiences and almost always includes hidden stories and themes. “I like to watch somebody look at a piece of art and try to figure out what it’s trying to convey.”

“Prophecy Awakening,” a mosaic-style painting of hands releasing objects holding tiny people into the air, explores the idea that we all belong to a community that helps us discover and release what’s inside of us. This is a fitting theme for Thwaites—after all, few people understand the benefits and risks of belonging to a community the way he does. After living with HIV for more than 25 years, Thwaites has grown close to many people only to watch them die. He used to belong to a support group—every single member died over the course of just one summer.

And out of 27 people who originally sought HIV treatment at Halifax’s Victoria General Hospital in the mid-80s, Thwaites is the sole survivor.

It hasn’t been easy, but Thwaites continues to reach out to other people with HIV by teaching art workshops, joining support groups, even sitting with people in the hospital as they prepare to die. “The person who survives doesn’t just take the sadness of losing someone,” he says. “The person who survives also takes the love and joy that person shared with them in their life. It’s not all about the loss. It’s also about what you’ve gained.”

In Thwaites’ experience, joining a community of people with HIV to share experiences about doctors, medications and side effects equips many people with the information they need to stay alive. “I think support groups are the greatest thing since sliced bread. That’s what it’s all about—listening to other people who are in the trenches dealing with it.”

Thwaites says that doctors and nurses sometimes sugar-coat HIV information, but he insists on giving and receiving the cold hard truth. It may annoy people, he says, but his truth-seeking nature is probably one of the reasons he’s still around.

“I’m the one at the conferences with my hand going up every five seconds,” he says with a laugh. “People look at me and think, ‘Oh no, he’s in the room. Is he going to say something?’ But if you don’t ask a question, you don’t get clarification and then you don’t understand. And if I don’t understand, I’m pretty sure whoever’s sitting next to me doesn’t either. I tend to be a bit of an activist that way.”

In 2009, Thwaites became a minister and helped start a new church in Halifax called Angel Hall. His spiritual side surfaces in many of his paintings, which depict angels and resemble stained-glass windows. His most recent paintings of hands grasping and releasing butterflies reveal that he’s ready for change in his life. “Next year will be my 50-year mark,” he says. “What’s beyond that? I’m not sure, but I see my art carrying me through.” +



Joe Average

One of the reasons I got myself a camera was to document the physical and emotional changes I have been going through with HIV and lipoatrophy. I found myself staring in the mirror and getting upset often. I was becoming increasingly depressed because of these irreversible changes. I decided to document the transformations, make art out of the experience and try to look at it from a different perspective.

I've done a few photo sessions with myself over the past few months. This photograph is from one of them. I am very happy with it because I think it portrays many different emotions.

I've been pretty shy about going out in public, which is something I'm trying to wade my way through and deal with. At one point I had the idea of wearing a burka-

like scarf over my head. This particular photo session was to see how that would look. After taking several shots with my head almost completely covered and just my eyes showing, I found that the images looked scarier than what I looked like. I was glad that I had the camera to help me see that.

I shot this photo on the deck of my apartment. It was a cold day so the scarf

worked well. The wind had picked up and I found that if I tilted my head to the side, the wind wasn't hitting me in the ear. I kept ducking the wind and tilting my head and I just kept shooting.

The photograph sums up a few things: my quiet low energy, the dramatic weight loss and the fact that I've kind of been hiding. It is the perfect self-portrait for that moment in time. +

Self-portrait

06.29.11

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