

THE POSITIVE SIDE

HEALTH INFORMATION & VIEWS

WINTER 2015 VOLUME 17 ISSUE 1

Ways to
love the one
you're with

The diabetes drill

Managing
chronic pain

Murray
Jose-Boerbridge's

HIV DIARIES

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EDITOR'S LETTER

If you picked up this magazine because you were intrigued by the disarming smile of the man on the cover, you won't be disappointed. Meet Murray Jose-Boerbridge, a man with an impressive mind and huge heart. In our cover story, "Crossing the Threshold," Murray shares his personal journey with HIV—from being diagnosed as a young university grad, to worrying about taking HIV meds, to dreaming of being a father. Now, as a proud dad, he reflects on the life-changing moments that have shaped the man he is today.

Murray draws inspiration from *The Lord of the Rings*: "Thus it is with thresholds, whether physical or psychological. Once you cross them, everything changes and there is no turning back." Indeed. Sometimes a threshold is physical, sometimes it's psychological—and sometimes it's both. Like an HIV diagnosis or achieving an undetectable viral load.

We explore the latter in Chatty CATIE, to find out what being undetectable actually means for people who are. Four people with HIV chronicle their "road to undetectable," and their answers might surprise you.

The theme of life-changing events continues with Art Posi+ive's conceptual artist Shan Kelley, who, like Murray, had ruled out having kids after his diagnosis. He now talks about life as a young dad and using art to subvert stigma. For Elder Claudette Cardinal, our Visual AIDS contributor, transformation began at an inspiring leadership training for HIV-positive women.

Also in this issue: An update on medicinal marijuana in Canada. Darien Taylor makes the case for self-care. And Doug Cook serves up strategies for controlling diabetes. Finally, if you are living with chronic pain, you'll want to check out Ask the Experts for advice on how to take the edge off.

Whether you read this winter issue over a cup of hot chocolate, curled up under a blanket or while soaking in the tub, we hope you enjoy it! As always, we'd love to hear what you think about the magazine. As the new *Positive Side* editor, I invite you to drop me a line at dkoenig@catie.ca

—Debbie Koenig

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Meet the Bloggers

CATIE educator **Melissa Egan** takes us on a tour of the HIV blogosphere.

Lately writing online has become an exercise in counting to 140—the character limit of a tweet. While modern technology makes it easy to keep things short and snappy, we do sometimes want a few more words! So we're getting to know some folks who prefer to express themselves in paragraphs, and we'd like to introduce you...



PHOTO: CASEY K PHOTOGRAPHY

The A Word
hivcl.org/category/blog

With their blog “The A Word,” staff at the newly renamed HIV Community Link (formerly AIDS Calgary) have built upon their great skill of engaging people in the work they do. Communications coordinator Weston Jacques and the other HCL bloggers keep the content fresh with stories for people living with HIV, updates on agency events, safer-sex tips and information about new developments in HIV research. The blog, an integral part of HCL’s website, highlights the voices of those living with HIV alongside cutting-edge facts pulled from sources around the world. Some entries link to videos and news stories while others capture changes in human rights, HIV testing and harm reduction.

AIDS New Brunswick
aidsnb.com/blog

The AIDS New Brunswick blog provides quick access to the latest agency news and events. Staff post pictures of AIDS Walk fundraisers and community happenings while making sure their readers know about what’s making headlines around the world. On the Poz Blog page, HIV-positive New Brunswickers share experiences and ideas, and inform others about community events.

In reading the blog, it’s easy to see how lively AIDS New Brunswick is: Its resourceful approach to community engagement has iPad winners grinning next to staff members. They even devised a unique way to show support for people living with HIV while raising awareness at the same time. Profits from the sale of red hair extensions sold by local hair salons are donated back to the agency as part of a World AIDS Day fundraising event. This group’s got substance *and* style!





Talk to the Hump

talktothehump.blogspot.ca

"Talk to the Hump" offers a unique opportunity to spend time reading about the personal journey of a Montreal man who has been living long-term with HIV. Ken Monteith, a lawyer-turned-HIV-community-worker and now executive director of COCQ-SIDA, a coalition of Quebec AIDS service organizations, describes it as "the ravings of a gay man living with AIDS and lipodystrophy."

Among Monteith's musings, he writes about having an MRI, giving readers a peek into how the process unfolds for him, which he quickly follows up with a long post on the movies he's recently seen. It is that juxtaposition that makes "Talk to the Hump" so much fun to read and attracts more than 2,000 people a month around the world. In this spirited place, you'll find a clear voice that shows readers the many facets of the life of a man who just happens to have HIV.

PHOTO: JEREMY SCHRUDER



The CATIE Blog

blog.catie.ca

CATIE now has its own blog! We've launched it to build an online community where people from across the country—and beyond—can engage in conversation about HIV and hepatitis C.

For the inaugural post, CATIE's Executive Director Laurie Edmiston reflects on the International AIDS Conference, in "What hit hard at AIDS 2014." Staff post regularly—pieces that we hope will inspire you to post your own reflections on everything from new research to health and social issues—and guest writers will share their stories as well. We hope to spark conversation about what it's like to live with HIV and hepatitis C in Canada while also offering the latest information about treatment and prevention from international conferences. Your participation will be a huge part of our success.

IF YOU'RE STILL SEARCHING FOR MORE...

My Fabulous Disease

If you haven't checked out Mark King's powerful and provocative video blog, you're in for a treat. Every post is an invitation into his life. As an HIV-positive man in recovery from a meth addiction, his unorthodox approach and unabashed joy for life provide an original and often hilarious perspective on life with HIV. For more about Mark and his journey, head over to marksking.com

I'm Still Josh

Weeks after creating a video of his HIV diagnosis two years ago, 29-year-old Josh Robbins launched this blog aimed at combatting stigma. His website is a cacophony of links, videos and comments from people living with HIV. Be sure to visit his Encouragement Wall for heartwarming and confidence-building words that will brighten your day. Get to know Josh at imstilljosh.com

Last but not least, you'll want to bookmark PWN and PositiveLite. We've highlighted these Canadian blogs before, but they're worth mentioning again.

Positive Women's Network (PWN)

The women at PWN—Janet, Erin, Monique and Miriam—blog about everything from sex and stigma to media and menopause. These women sure do their homework! They're all a pleasure to read and you'll likely end up learning something new. Find them at pwn.bc.ca/blog

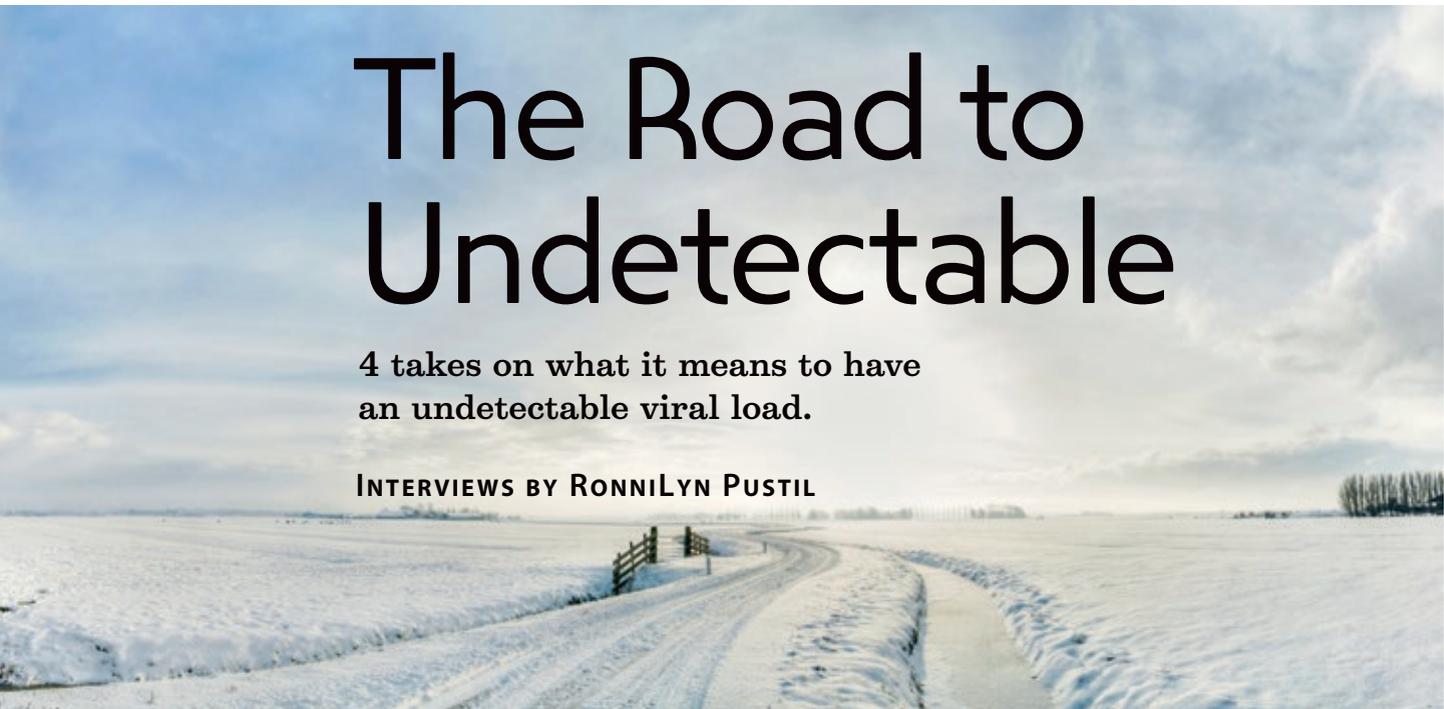
PositiveLite

One of the most comprehensive online HIV magazines, PositiveLite is where you want to go to find cutting-edge information, rich social commentary and excellent writing about HIV. With a wealth of contributors and compelling topics, it's easy to lose a few hours bloghopping. Check out PositiveLite.com

The Road to Undetectable

4 takes on what it means to have an undetectable viral load.

INTERVIEWS BY RONNILYN PUSTIL



DAVID H., 49
Southern Alberta
HIV+ since: 1984
CD4 count: 224
Undetectable for: 8 years

By 2006, I had become resistant to all the HIV meds out at the time. I was supposed to die, but thankfully new drugs soon became available. I've been on my drug regimen for eight years now—and my viral load has been undetectable for nearly as long.

Being undetectable with a CD4 count of 224 makes for a bumpy ride. I

try to hang on and not let it get to me. I am fortunate enough to not have to deal with financial issues because just existing is a battle onto itself.

Being undetectable reassures me that I am less likely to transmit the virus to others. This helps me to stigmatize myself less. It is tiresome to see on all the dating sites the words “must be clean and disease-free.” The connotation of the word *clean* negates the fact that I am undetectable and it's insulting to anybody living with HIV. Education is a slow-moving rock where I live. It gets crushed by fear and a lack of understanding.

Being undetectable in Southern Alberta is not the same as being undetectable in, say, Toronto, where there is much more awareness. Going to a larger city often boosts my morale and confidence immensely.

I live in a town with a population of 100,000 where “treatment as prevention” [the idea that HIV treatment and having an undetectable viral load dramatically reduces the risk of HIV transmission] means nothing to many

people. This is the Bible Belt. Most people here still seem to think that HIV is a death sentence, and second-year nursing students still believe they can get HIV from a handshake.

Being undetectable makes me feel like I am doing my job. I take my drugs on time every day. I feel proud when my HIV doctor asks if I've missed any doses and I can say no. My healthcare providers have given me the tools to do this. But being undetectable is not enough. In return I give back to my community with many hours of charity work. It all comes full circle.

MURRAY HODGE, 56
Toronto
HIV+ since: 1995
CD4 count: 630
Undetectable for: 9 years

Prior to viral load testing, the main tool to monitor your health was your CD4 count. Once viral load testing came into the picture, it was all about striving to be “undetectable” and reducing the amount of HIV in your

blood to levels so low that a viral load test would not be able to detect it.

I feel good when I get that undetectable result every three months. It's always the first thing I ask my doctor about. It means that I don't have to change my treatment and that everything is fine until the next time I get my viral load checked. It's encouraging, a positive affirmation that I'm doing well. I have multiple drug resistance, so not having to change my regimen is a great relief.



I've had a few blips over the years but when we've done a follow-up I've been undetectable again every time. When there's a blip, I get concerned but I don't worry that we won't be able to manage it. I feel like everything is easier to manage now when it comes to my HIV. **My focus now is on living longer and growing older** with HIV and all of the issues that come along with that.

TRACEY NOLAN, 44

Stephenville, Newfoundland

HIV+ since: 1997

CD4 count: 464

Undetectable for: just over a year

I was diagnosed on September 13, 1997, a little over a week after having a miscarriage. I had an HIV test because in Newfoundland all pregnant mothers were routinely tested. I started treatment a month later—ritonavir and saquinavir, just those two meds for 10 years. The doctor at the time gave me a grim outlook but the HIV nurse assured me I would be OK.

My latest CD4 count was pretty good considering I went off meds for five months almost a year ago due to

financial struggles (copayment being almost as much as my paycheque). It was a scary visit with the HIV clinic team when I was told that my CD4 count was 163 and my viral load was very high. My son was with me in the doctor's office and when he started to cry, it set off the flood of tears I was trying desperately not to release. For the first time in 16 years, I came face to face with my mortality and thought, "This is it. I am going to die."

There was a dark cloud but once my viral load went back to undetectable soon after I went back on HIV meds, the sun came out and I could breathe again. It's a great relief that I am not resistant. Before I went off meds, I had been undetectable for 13 years.



Being undetectable gives me hope for more options in the future. It means keeping opportunistic infections at bay. It lets me focus on things other than the fact that I'm a host to HIV.

I try to remain positive even when I'm scared. When I'm feeling ungrounded, I smudge, which gives me a sense of balance. There are so many who have passed on with this illness that I feel I must maintain a sense of gratitude for being able to celebrate life every day, even the shitty ones.

GORDON WASELNUK, 65

Vancouver

HIV+ since: 1989

CD4 count: 550

Undetectable for: 5 years

I have been surviving and sometimes thriving with HIV for 25 years. I have seen friends and lovers die. In the early years, there was a lot of mistrust

of the pharma industry, as it promised us treatments that did not deliver or that left us struggling with nasty side effects.

Today the meds seem to be so much better and I have been doing very well on Atripla for the last five years. Although my viral load is undetectable, in the back of my mind I wonder if the wheels will eventually come off again. For many years I was told to think positively but to be prepared for the worst. It is hard to totally let go of the past and change that mindset overnight.



I feel like I am in the process of coming out again—a little hesitant, reluctant and nervous—as an undetectable HIV-positive man. According to many studies, people who are undetectable may live normal lifespans and are far less infectious. I still practice safe sex just in case. It's like I'm in a transition phase and am gradually gaining more confidence and self-respect. I feel that being undetectable is something to be proud of. When I step back I realize that we are leading the way to reduce HIV in our community.

We need to rebrand. The words *HIV* and *AIDS* are loaded with 30-plus years of fear, shame and stigma. I want to let go of all that. How about *Undetectable and Proud!* I look forward to a future when we can all come out and celebrate. +

For more on what it means to be undetectable, check out AIDS Vancouver Island's "The New Face of HIV" campaign at aidsvancouver.org/undetectable



Crossing the Threshold

Murray Jose-Boerbridge tells the story of his journey with HIV.

PHOTOGRAPH BY MICHELLE GIBSON

When members of what would become The Fellowship of the Ring crossed the threshold into Bilbo Baggins' home, they knew that their lives were about to change forever. They would not be able to walk back across that threshold the same person. Thus it is with thresholds, whether physical or psychological. Once you cross them, everything changes and there is no turning back.

Those words are from an article I first wrote for GayGuideToronto.com (now TheGayGuideNetwork.com) in September 2003. The idea of momentous thresholds may be all I have in common with *The Fellowship of the Ring* but it resonates powerfully. My HIV diagnosis in 1991 was one such

moment, as was starting HIV treatment. Becoming a father was another. All have profoundly changed me and shaped the person I am today.

I have always enjoyed writing and found it therapeutic. Through it, I can challenge people's assumptions, honour history and offer my perspective on poignant moments. When preparing to write this piece for *The Positive Side*, I read over articles and speeches I've penned over the years, reflecting on my experiences, opinions and relationships. Here I've included some excerpts I wrote primarily for TheGayGuideNetwork.com's monthly column Poz POV, about my own pivotal moments.

Living with HIV and working in AIDS service organizations (ASOs) since 1994 opened my eyes to social justice issues, discrimination and homophobia. This took me a long way from my sheltered childhood on a dairy and orchard farm east of Toronto.

I left home at 17 for Wilfred Laurier University in Waterloo, Ontario. My coming-out experience was like getting a bucket of water in my face—oh my god, I'm gay. A tattoo and ear piercings soon followed. After graduating from university—with a BA in psychology and later a diploma in human resources management—I was managing a restaurant in Kitchener, Ontario, and realizing that hospitality was not going to be the career I had hoped for. That's where I was in 1991 when I got my diagnosis. I was HIV positive. I was 23.

I gravitated to working for ASOs. It dawned on me then that my race, gender, socio-economic status and education have afforded me certain privileges. And so I've chosen to work in a very public way, because for me there are fewer repercussions than for many others—I didn't have to worry in the same way about disclosing my status to family, coworkers or friends, or about losing housing.

It has helped, too, that I've always liked being different—for instance, I deliberately didn't drink until I was about 35, partly because at school

drinking was expected. It also helps that I enjoy challenging people's perspectives. When I began to speak publically in the '90s about being positive, for instance, students thought they would be able to "tell" if someone was HIV positive but I looked very much like them—young and healthy.

At that time there was a lot of pressure to go on HIV drugs, but I pushed back because my immune system was strong. For 12 years that decision continued to make sense—until starting a cocktail became the wise course. That change loomed as another enormous threshold, and I wrote about the prospect, with some anxiety, in 2003.

I expect that I will soon cross a psychological threshold that will change me forever. I will start the cocktail for the first time. This is not just about starting new drugs. This is changing a part of my identity.... There are lots of emotional elements to that identity. For the last few years, I have considered myself a long-term non-progressor. Significant parts of my identity will now have to change.

A few months passed before I started treatment. In June 2004 I wrote about new worries.

This spring marked the beginning of taking HIV drugs for me. You'd think that my knowledge would help me to be more intellectual than most and dismiss unrealistic fears around health and side effects. Somehow, intellect doesn't seem to have much impact on fear, realistic or not.

*Is that a rash or a sunburn?
Am I looking a little jaundiced or is that the fluorescent lighting?
What is the difference between being tired and being fatigued?
Is that belly the beginnings of lipodystrophy or last night's pizza?
What is the threshold between feeling a little blue and being depressed?*

Looking back, I see how fortunate I was. I began treatment at a time when

researchers already knew so much about medications and best dosages. I'm still on my second cocktail and other than a kickass bout of depression from efavirenz, which resulted in me switching regimens, I've had no side effects. My viral load has been undetectable since a few months after starting treatment.

My good health and a new job with the Toronto People With AIDS Foundation (PWA) allowed me to push myself in an entirely different way—for a total of six years: In spring 2005, I signed up for PWA's annual Friends for Life Bike Rally, which sends cyclists and crew on a six-day, 600-km journey from Toronto to Montreal.

Although growing up I had liked to swim and run, and I was in reasonably good shape, the rally was still challenging. I solicited donations and took advantage of available training most weekends for four months leading up to the event my first year. That first ride, in July 2005, was intense physically and emotionally—and incredibly exhilarating. Upon arriving in Montreal, I reflected on the experience.

It can be overwhelming for me to think of the many motivations that have played a part in bringing me here to this point of having cycled from Toronto to Montreal over six days. Among them:

- *I can do anything I set my mind to.*
- *HIV will not limit me.*
- *You cannot make assumptions and label me.*
- *I will shatter my own perceptions of what I am capable of.*

For me, storytelling is a way of preserving history in a personal, meaningful way. I think of how I may be the only one who remembers certain individuals who have died. I think about the experiences that so often isolate us from family and community. Remembering helps to motivate me. I wrote about this in February 2007.

Will we be remembered? Not just as individuals but as a community

that responded to a devastating disease with creativity, love, anger and a resolution that we would not let this disease destroy us.

We forced the medical community to see us as partners in our health care, not just patients blindly doing as we were told. We forced government to change policy and access to medications. We created a new way of celebrating someone's life that is so much more unique and creative than the traditional funeral. At the same time, we were struggling with loss on a massive scale.

As a person diagnosed HIV positive in 1991 and living with a partner nine years my senior, I watched as my partner's group of friends was decimated....

When funerals were planned, families excluded friends and volunteers who had helped the person die with dignity. Boxes of unclaimed ashes lined the shelves....

I understand that our communities are tired, that many long-term survivors have become isolated and exhausted. People have chosen to move ahead with their lives and perhaps feel that the history is not important in shaping the present. How incredibly sad that makes me.

Thankfully, my life has been filled not just with grief and sadness but with great joy. There were very few dreams that I had allowed HIV to impact, but raising children was one of them. For a long time, I just didn't think it was going to be possible.

In August 2005, I wrote about spending time with my nieces and some friends' daughters.

- *There is something inherently beautiful about holding a child in my arms.*
- *There is a responsibility to myself and to the child to be the best person I can be.*

Even when my partner and I decided to explore adoption, I assumed there was no way children's services would consider someone with my health concerns.

- *When I'm with a child, I see the wonder in everything. A simple flower can be the most incredibly beautiful and complex thing in the world.*
- *Being with a child keeps me grounded and focused on what is important.*

Eight years later, my partner and I adopted our 18-month-old son. I was 45. To my surprise, the fact that I'd been HIV positive for nearly 20 years ultimately hadn't been a barrier.

I had let go of parenting not just once, when I understood myself as a gay man, but several times—also after my HIV diagnosis and again when exploring sperm-washing options with friends. Even when my partner and I decided to explore adoption, I assumed there was no way children's services would consider someone with my health concerns.

As a person living with HIV, it was one thing to make long-term plans and dream on my own or with my partner. It was another thing entirely to make the commitment to raise a child. I have

strong memories of getting to know my father when I was grown up, as two adults, and I wanted that opportunity with my son. While still very much scared and uncertain, I took the plunge.

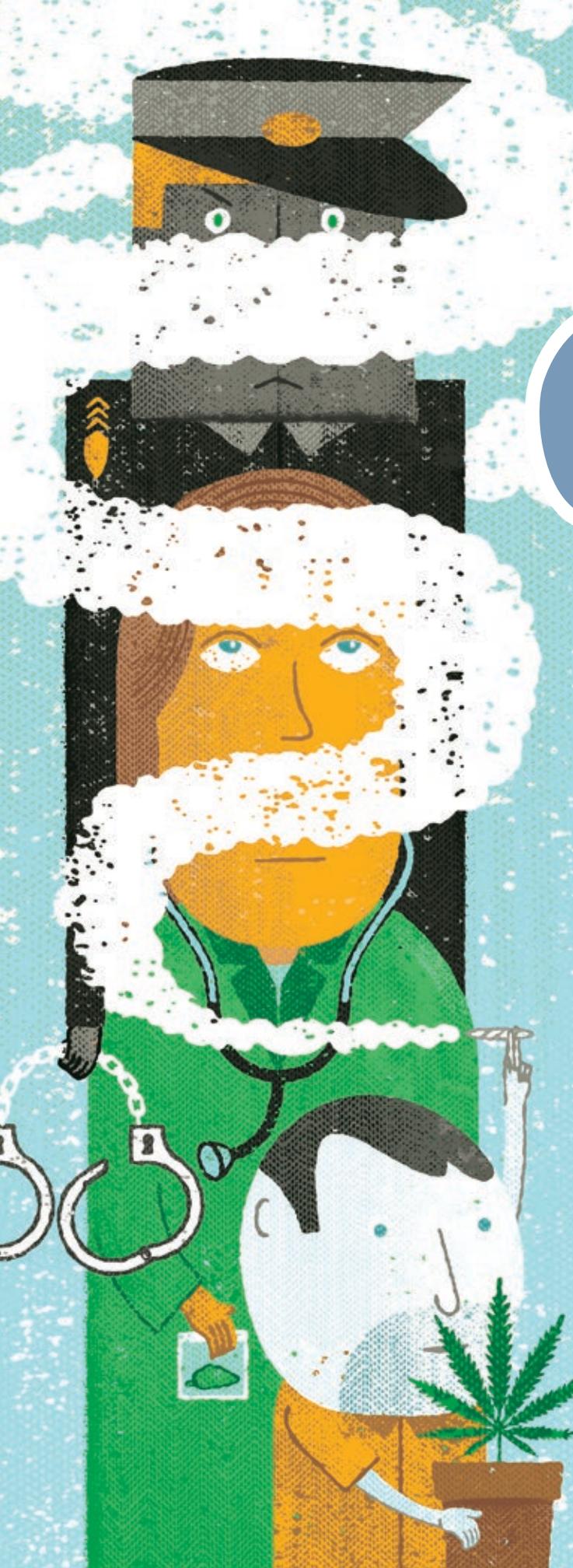
Fast-forward to the moment I saw our future son looking out the window of his foster mother's home as she pointed us out pulling into the driveway the first time. I can't even write that sentence without tearing up at the memory. A threshold indeed.

I had a sense of the wonder with which I would see the world, as through a child's eyes, but of course the reality is so much more intense. Everything is new and fascinating. He has opened new doors to the person I am, the assumptions I hold of myself and the perspectives with which I see the world.

For two gay men parenting a child, there is occasional discrimination or even risk, particularly when travelling. But I have been surprised by the unexpected smiles, comments and connections that are elicited simply by walking down the street with our son.

My son's world will be different from the one I've inhabited. One day I will talk to him about HIV, normalizing it as much as possible. He will connect to it and to gay identity (regardless of his own sexual orientation) in ways I can't imagine. He will be part of a world that may be distanced from the loss and impact of HIV that I experienced. But I hope it will be a world connected to the passion, community and strength that resulted. +

Since 1994, Murray Jose-Boerbridge has worked at ASOs in Guelph, Cambridge, Kitchener and Waterloo, Hamilton and, for close to 10 years, as executive director of the Toronto People With AIDS Foundation (PWA). He is also founding co-chair of the Ontario HIV Treatment Network, co-chair of the Toronto HIV/AIDS Network, and member and chair of the Gay Men's Sexual Health Alliance Poz Prevention Working Group.



Smoke Signals

With medicinal marijuana laws in a state of limbo, where do things stand for people who count on it? **Peter Carlyle-Gordge** gives us the straight dope.

ILLUSTRATIONS BY IAN PHILLIPS

Thousands of people living with HIV in Canada find cannabis critical for managing their illness—for appetite stimulation, weight gain and relief from nausea, pain, anxiety and depression. Rosa Colavito-Palao, a therapist at Nine Circles Community Health Centre in downtown Winnipeg, sees many clients with HIV and other health conditions for whom pot has proven to be a godsend. “People have experienced great medicinal benefit and great physical relief from their pot use,” she says.

THE CANNABIS CONTROVERSY

One such client, Chris, a 49-year-old man, has been smoking pot for medicinal purposes for decades. He used to work as a cook in Northern Manitoba's mineral-drilling work camps but had to leave his job and go on employment insurance due to debilitating illness and fatigue. Diagnosed with HIV in 1986, when he was just 21, Chris uses pot to relieve the nausea, gut troubles and other side effects of his HIV treatment. "Without it, I don't think I'd be able to eat," he says. More recently, the herb has helped him with other health problems. Due to Chris' immune system being "totally shot," a severe brain injury seven years ago produced neurological pain, balance and mobility problems. Smoking marijuana has helped with all of these symptoms. "I need my pot for chronic pain," he says. "It gives me appetite and energy—without it, I'm totally lethargic and it takes me an hour or more to walk to the clinic." Chris pays around \$10 a gram and, because of his low income, rations it carefully.

For people like Chris who use marijuana for therapeutic purposes, the changing headlines and news stories have made it hard to get a picture of where things stand when it comes to medicinal marijuana in this country. So what do we know about how the laws have changed and what lies ahead?

MARIJUANA AS MEDICINE

Cannabis—aka weed, herb, dope, pot—is technically illegal to buy, use or possess in Canada. But back in 2000 the Supreme Court ordered the federal government to come up with a scheme that would allow some people to use the drug for medicinal purposes. In response, Ottawa set up a system whereby people had to apply to Health Canada for an authorization that would allow them to possess limited amounts of medicinal marijuana bought from a government-approved supplier or get a license to grow their own pot for personal use or designate someone to grow it for them.

When Canadians were first authorized to possess marijuana for medicinal purposes, there were fewer than 500 legal users; Health Canada estimates that there are now approximately 40,000. Scores of compassion clubs mushroomed across Canada to meet the need and provide a safe supply of the product. They argued that the government-approved pot was costly, the quality was unreliable, and doing all the paperwork needed to get the required approvals was daunting.

So dozens of compassion clubs have been acting as dispensaries of medicinal marijuana to people with a wide range of health issues, including HIV, peripheral neuropathy, cancer, multiple sclerosis, epilepsy and other conditions. They have operated in a grey legal area and, more often than not, the police has turned a blind eye to them (though compassion clubs have certainly been busted—check out "Cultivating Compassion" in the Summer 2007 issue of *The Positive Side*).

Health Canada does not license or support compassion clubs and still regards pot as a dangerous, unproven

"I think it should be decriminalized, since medicinal users have plenty to worry about without fearing police knocking on their door.... You can legally buy and use marijuana in Washington and Colorado now, but in Canada we seem to be going backwards. The government is making it harder for sick people who need this medicine to get hold of it.

Pot has helped me enormously to keep on going. I don't think the government has any business interfering with how I get a proven medicine that has helped many of us cope."

—Chris, living with HIV for 28 years

"We want to remind Canadians that marijuana is not an approved drug or medicine in Canada. Health Canada does not endorse its use."

—Health Canada press release, March 31, 2014

"The simple solution is to decriminalize the drug. This would remove barriers to obtaining it and eliminate fear of arrest by people who are already coping with major life challenges. There are people who grow their own pot and feel very comfortable ingesting or smoking it because they know exactly what it is and where it came from. Perhaps there could be room for people who wish to buy regulated pot as well as those who wish to grow their own."

—Rosa Colavito-Palao, therapist,
Nine Circles Community Health Centre

"The Canadian Medical Association remains adamant that it will not throw its support behind medical use of the drug until numerous questions about safety, efficacy, dosage and delivery have been answered."

—Canadian Medical Association

medicine. Yet a decade ago, the Senate blasted the Canadian government for ignoring the considerable experience and expertise of compassion clubs. A Senate report stated that government regulations failed to facilitate access to therapeutic cannabis and that "the continued prohibition of cannabis jeopardizes the health and well-being of Canadians much more than does the substance itself." It recommended that Health Canada take measures to encourage the development of compassion clubs.

NEW RULES

Fast-forward to 2014: Last April, Ottawa brought in new regulations. It abolished the right of individuals to grow their own pot and invited for-profit companies to start supplying it. Several companies are anxious to jump in so they can get a piece of the legal pot pie. It is estimated that by 2024 the industry will accrue \$1.3 billion in revenues.

Under the new rules, growers have to meet strict security and quality standards and they have to notify local police as part of their application to become a licensed producer.

By Health Canada's own estimate, the number of licensed consumers of medicinal marijuana will increase almost tenfold in the next decade, to approximately 309,000, as more evidence of the drug's efficacy emerges and as more doctors become willing to prescribe it to their patients.

Under the new Marijuana for Medical Purposes Regulations (MMPR), doctors in effect become the gatekeepers, determining who can legally gain access to pot. It's a role many physicians are reluctant to take on.

Previously, people who applied to the medical marijuana program had to have their application form signed by their doctor, which indicated that the physician was aware that their patient was using pot for medical purposes, but Health Canada had the ultimate say. Under the new rules, users simply seek a document from their doctor, similar to the way one would get a prescription.

BURNING QUESTIONS

These changes have raised some burning questions: Do the new laws mean that private growers who are currently licensed will have to destroy their crops and get rid of expensive equipment they bought to grow it? Will commercial companies be able to jump right in to provide adequate supply to the people who need it or do people who depend on medicinal marijuana need to worry about a dry spell?

Unlike compassion clubs—which have dispensed marijuana in the form of capsules, creams, tinctures, food products, extracts and concentrates—licensed companies can only sell dried marijuana buds. So another concern is, if pot will only be sold as dried leaves for smoking under the new regime, what does this mean for the users who are not able to smoke it for health reasons—such as people with lung cancer or chronic obstructive pulmonary disease—and can only ingest it in other ways?

Compassion clubs have been able to make these various products available along with counselling on marijuana and health issues. Most doctors lack such expertise yet they are to be the sole gatekeepers of who gets to use medicinal marijuana.

Last but not least, there are concerns about price. Dried marijuana from licensed companies ranges in price but is generally far more expensive than dried marijuana purchased from Health Canada or grown at home. Like Chris, many users of medicinal marijuana have limited incomes and cannot afford higher prices.

LEGAL CHALLENGES

The new regulations, which ban individual growing, were due to kick in April 2014, but thanks to court challenges, those authorized to grow, buy and use pot under the old

rules can continue to do so for now. The old system remains legal until a lawsuit is settled in a Vancouver court.

A B.C. judge sided with a patient coalition, arguing that the new regulations violate the patients' Charter rights to health and liberty. He granted an injunction allowing current patients to keep growing until a final ruling is passed down. The judge agreed that the new program does not provide adequate access and that some patients will be unable to afford marijuana at the licensed producers' prices.

In another case, four plaintiffs are challenging the arbitrary and restrictive nature of the new regulations; this federal court case, expected to last three weeks, will begin in a Vancouver courtroom in late February. Some of the plaintiffs have grown their own pot to ensure quality, safety and efficacy and have invested substantially to do so. They say that they found the black market as well as the single government-approved provider, Prairie Plant Systems, unreliable sources for consistent quality. Moreover, they claim that the new regulations are arbitrary and unreliable.

The Harper government plans to fight this Charter challenge.

Whatever the courts decide, it's a pretty safe bet that many people will continue to buy their pot on the black market, because they're either unable to afford the prices of the new legal suppliers or unable to find a doctor who will prescribe it. It's doubtful that those people who are now buying pot illegally will rush into the new system.

The ultimate resolution may well be political. Liberal Leader Justin Trudeau favours legalizing pot, which will undoubtedly attract some electoral support from users. "I did a lot of listening, a lot of reading and a lot of paying attention to the very serious studies that have come out," Trudeau said, "and I realized that going the road of legalization is actually a responsible thing to look at and to do." With a federal election due in 2015, party leaders will likely be on the hot seat to explain precisely what they plan to do about medicinal marijuana. +



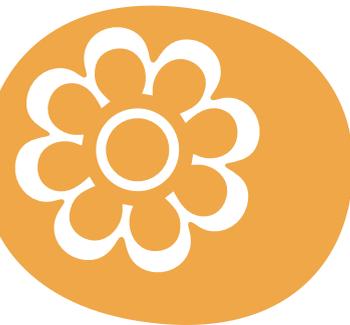
To find out how you can apply for medicinal marijuana under the new MMPR, visit www.hc-sc.gc.ca/dhp-mps/marihuana/access-acceder-eng.php

Winnipegger Peter Carlyle-Gordge is a former writer for *Macleans*, *Time Canada* and *The Financial Post*. He has also worked as a CBC Radio broadcaster and producer and is a former UK correspondent for the *Toronto Star*. In the 1980s he was president of the Village Clinic (now Nine Circles Community Health Centre).



Show Yourself Some

LOVE



**Think self-care sounds
self-indulgent?
Think again.**

BY DARIEN TAYLOR

effective antiretroviral therapy has given people with HIV our lives back. But with this new lease on life can come responsibility and, for many of us, stress. Along with all the ordinary tasks of life, we are living with a demanding chronic illness. We juggle doctors' appointments, blood work and medication schedules with employment, school or taking care of our loved ones—or all three!

With all of these responsibilities, it's easy to lose your equilibrium and forget to put yourself first. When life has you in a stranglehold, it might seem hard to give yourself permission to, say, not take phone calls during dinner. But people with HIV from across the country affirm that putting time aside for self-care is crucial to our survival and well-being.

WHY IS SELF-CARE SO CRUCIAL?

When you've got a lot on your plate, caring for yourself can seem selfish and indulgent—something to feel guilty about. We might feel that it isn't "right" to do things that are purely pleasurable. We might have internalized a message that we should "do without."

But, in fact, you need to take good care of yourself in order to be available for those who are important to you. Ignoring your own needs can make you sick or can worsen existing health problems, whereas cultivating self-care practices can bring meaning and fulfillment to your life. As you care for yourself, you will find that you are more present, caring and available to others, less likely to "lose your balance" over time and, when challenges arise, more able to quickly restore it.

HOW TO TELL WHEN THE BALANCE IS TIPPING

Claudia Medina, a 42-year-old Latina woman who has been living with HIV for two decades, had met her life goal of working in an AIDS service organization. Her colleagues were “awesome” and her work was meaningful. But her job as an advocate for prisoners and ex-prisoners was also stressful: The issues of oppression she was dealing with on a daily basis eventually took a toll on her personally. She knew something was wrong when she realized that although she spent her days getting proper identification for the people she worked with, her own passport had expired and her SIN card needed to be replaced. And she wasn’t finding the time to do her yoga, work out or take her vitamins.

Medina’s supervisor could see that she was starting to lose her equilibrium and suggested that she limit her committee work and stop taking work home with her. Looking back, Medina realizes that she wasn’t giving herself permission to care for herself. “I wanted to do everything for everybody,” she says. “I had this feeling that if I didn’t do it, it wasn’t going to get done.”

Her stress began to show itself on a physical level: She gained weight and became increasingly forgetful. Her organizational and time management skills deteriorated. Even though she had written herself reminders—on her phone, on her computer and in her daytimer—she forgot the dates of important workshops and details about where she was giving presentations. She started to wonder if she was experiencing HIV-related neurocognitive problems.

Gradually, Medina stopped socializing and became more isolated. She found it difficult to relax and sleep at night, and she found herself drinking more on the weekends to unwind. The twin demons of anxiety and depression, which she has dealt with throughout her life, were harder to keep under control. “There was so much negativity in my life. My personal life was spilling over into my work, and I was having meltdowns at work. Every day began to feel like a chore, and it was hard to get up in the mornings.”

Tom Hilton didn’t realize that he had lost the balance in his life until his family and friends held an intervention. “Stimulants, especially coke, crack and meth, were big for me,” he says. The 49-year-old Prince Edward Islander now acknowledges that a sense of unworthiness and internalized homophobia compelled him to “run to anyone or anything that could take me away from looking seriously at myself.” These factors also kept him from learning about safer sex and HIV, resulting in his HIV diagnosis in 1992.

Luckily, Hilton had friends and family who cared about him. He ruefully admits, “I swallowed my pride, listened to what these people were saying to me and decided to move



Multitasking
is the devil.



back home to PEI and give myself a fair shot at a healthy life.”

Does any of this sound familiar? It does to me. By the time I decided that I needed to restore the balance in my life, I was feeling and doing many of the same things as Claudia and Tom. No energy for work? Check. Negativity? Depression? Anxiety? Check, check and check. Increased substance use? Check. Disrupted sleeping and eating patterns? Double check.

RESTORING BALANCE

People with HIV can learn to stay balanced through conscious self-care. It takes attention and practice. As Hilton says, “It isn’t easy to take myself seriously, it’s much easier to sabotage myself.”

3 simple questions

A journey of self-care can begin with three simple questions:

- What do I need more of right now?
- What do I need less of?
- What is causing me to feel stressed out? Why?

Now think of a simple activity you could do in the next week that would address your responses. For example, if you feel that the demands of family, friends or work are overwhelming, consider giving yourself a half-hour of daily “me” time. Turn off your phone, shut your door and listen to some soothing music.

Check in with yourself at the end of the week and see how this small intervention has made you feel. You may want to continue this routine, or you may want to switch things up, substituting the musical interlude with a warm bath by candlelight, for example.

Just say “no!”

It can also help to make an agreement with yourself about those things that you want out of your life: your “no!” list. This is part of developing healthy boundaries. For example, if your space is cluttered and chaotic, make an agreement to keep only those things that have meaning for you. Throw the rest out! Or have a garage sale! Other things that might go on a “no” list are: gossiping, fretting about the past, sleeping with your cellphone in the bedroom.

Post your resolutions in a place where you can see them. Share them with others so they understand what you are doing. But remember to be kind to yourself; if you slip, don’t beat yourself up, just pick up where you left off.

In Medina’s case, she resolved to avoid multitasking, which left her feeling unfocused. “Multitasking is the devil,” she declares. “I compartmentalize things much more now. I start and finish a task before moving on to the next one.”

Cultivate positive relationships

At first Medina thought it was going to be impossible to disengage from her work in the HIV sector because she saw

her identity as being so wrapped up in her job. “Now, I’m a different person,” she says. “I see that there are so many different aspects to my self. My body is starting to balance out, I sleep better and I no longer experience the side effects of hyperactivity and anxiety from my HIV medications.” She feels grateful for the support of family and friends, “especially my PHA friends. Lots of PHA friends have come back into my life—as well as new friends,” she adds, smiling.

Hilton believes that returning to Charlottetown to be close to his family and friends allowed him to set the boundaries he needed to develop healthy habits, like better sleeping and a more wholesome diet, and to think more clearly. “It is really courageous to recognize that we need the help of others,” he says. “I’ve been home in PEI for eight years now and living near my family helps to keep me on the straight and narrow.”

Back to health basics

Observing health basics also creates balance in Hilton’s life. Getting enough sleep is important, he says. “I try to get a nap in every day, if possible.” He works out regularly, eats “real food that I cook myself” and credits an honest, respectful relationship with his HIV doctor as an essential part of his self-care. “I take my meds practically every day,” he says. “I like having an undetectable viral load; it’s motivating.”

Montrealer Bruno Lemay agrees that going back to health basics is key. “When I get stressed out, I tend to bury myself in work and school. I can neglect my relationships and my physical health, and I end up feeling anxious and have trouble sleeping. So I hit the gym. Physical activity makes me feel better. I’m more relaxed and I sleep well. And when I feel better, I can be a better partner.”

Take yourself seriously

Hilton and Medina both feel that investing in themselves through education is an important element of their self-care. Medina has just returned to school to complete her studies in community work and social services at Toronto’s George Brown College, with the goal of eventually obtaining a bachelor of social work. Hilton recently graduated with a Master of Education from the University of Prince Edward Island and was awarded the Governor General’s Gold Medal for his thesis, *Schooling*

and Practices of Freedom of ‘Out’ Queer Youth on Prince Edward Island. He is currently working on a project with the PEI Human Rights Commission that will provide teachers with tools to engage with social justice issues in the classroom.

Take time for traditions and nature

Claudette Cardinal, a Cree woman living in Vancouver (see also Visual AIDS, page 26), finds that “city energy” can sometimes make her feel squirrely. When she starts to feel that familiar tightness in the pit of her stomach, she calms herself through traditional practices such as smudging with sweetgrass, cedar, buffalo sage and traditional tobacco. She knows a “sacred spot” in the forest in Stanley Park where she goes to find silence and ground herself.

Saltspring Islander Margarite Sanchez also looks to nature for solace. “If I’m really stressed, I’ll take a power walk in the forest or by the ocean,” she says. “That gets me breathing deep and I come back with a much clearer mind. Another super self-care strategy is having a hot bath in my outdoor cast-iron bathtub! That is my ritual every time I come home from the city. It melts all my worries away.”

Practice mindfulness

As for me, my physician’s referral to mindfulness-based cognitive behavioural therapy provided me with important tools to rebalance my life. Through a program that included exercises in meditation, deep breathing and goal setting, I have become more aware of my negative thoughts and feelings and how they were leading me to behave in unhealthy ways.

These examples from people with HIV show that self-care is very much an individual practice. There are no rules for how, when or what to do, though many mental health practitioners recommend taking 30 minutes a day to do something nice for yourself. So, go ahead and show yourself that you care! You’ll feel happier and healthier for it. +

Darien Taylor is CATIE’s former director of program delivery. She cofounded Voices of Positive Women and is a recipient of the Queen Elizabeth II Diamond Jubilee Medal, awarded to honour significant contributions and achievements by Canadians. Darien has been living with HIV for more than 20 years.



A Cheap and Cheerful Self-Care Exercise

At your local drug store, purchase a single-application face mask and a nice-smelling bar of soap. When you get home, turn on some soothing music. Give your hands and face a good wash in warm water with your new bar of soap. Pat your face dry with a clean towel. Now apply the face mask according to the instructions.

Lie down and feel the face mask do its work. Listen to your music. Be aware of your breath, as you inhale and exhale. After about 20 minutes, remove the mask with warm water, pat your face dry and look in the mirror at your beautiful face. There! You just practiced self-care!

The important thing here isn’t that your face is clean; it’s that you took the time to treat yourself well and make yourself feel good. There are lots of other ways you can practice self-care every day: eat your lunch in the sun, drink lots of water (add lemon or cucumber for flavour), stop and make yourself a cup of herbal tea, or buy yourself a magazine and read it in bed. Show yourself some love!





THE DIABETES DRILL

People who need help managing their diabetes have become the bread and butter for many dietitians and with good reason: The number of individuals being diagnosed with diabetes continues to climb. As a dietitian, I routinely see clients who have just been diagnosed walk through my door, wanting to know if they need to follow a special diet or how they can cut back on their sugar intake.

According to the International Diabetes Federation, 382 million people are living with diabetes worldwide and that number is projected to increase to a staggering 592 million by the year 2035. An additional 344 million people are estimated to have pre-diabetes, meaning that their blood sugar levels are high but not high enough for a diabetes diagnosis. Here in Canada, of the more than nine million who are living with either diabetes or pre-diabetes, almost half remain undiagnosed and are not getting the vital education, facts and care needed to manage this serious disease.

Art Zoccole knows all about it. The executive director of 2-Spirited People of the 1st Nations—an organization that provides counselling and social services to Aboriginal two-spirited, lesbian, gay, bisexual and transgender people—Zoccole was diagnosed with diabetes in the summer of 2003, just days after learning that he had HIV. “I knew something wasn’t right,” he says. “I was outside shivering in July and I had night sweats in the evening.” So

Doug Cook
on how to keep
your blood sugar
in check.

he admitted himself to St. Michael’s Hospital in downtown Toronto, where he was diagnosed with HIV and, soon after, diabetes. Up until that point, he had no idea that he had either disease.

With effective HIV treatment allowing people to live longer, more and more cases of diabetes and other metabolic disorders are being detected in people with HIV as they age, not unlike the general population. Plus, certain factors specific to HIV—the virus itself, certain HIV medications, and HIV/hepatitis C coinfection—put a person at greater risk for developing diabetes.

What’s the big deal?

We’ve come a long way with how diabetes is managed. There are now insulin protocols, such as insulin pumps, that more closely mimic the way the pancreas (our insulin-producing organ) functions normally. Despite this, diabetes remains a serious disease. In my practice I’m continually surprised by the casual attitude many people have with respect to their diabetes, believing that they just need to watch their sugar intake and take their medication. The truth is, if left untreated or poorly managed, diabetes can have serious long-term consequences, including increased risk for blindness, kidney disease, nerve damage, heart disease and stroke. Diabetes is the leading cause of amputations and a significant contributor to erectile dysfunction.

But a diabetes diagnosis doesn't have to mean a lifetime of health woes. Like HIV, this chronic condition can be effectively controlled with a holistic approach—a healthy diet, regular exercise, medication, stress reduction, addressing any underlying psychological issues like depression or anxiety, smoking cessation and routine monitoring of health issues with a family doctor and other specialists as needed.

Keeping it under control

Controlling your diabetes and blood sugar levels is best achieved using a combination of lifestyle changes and, if needed, medication, such as insulin and/or an oral anti-diabetic drug like metformin. No medication can make up for a sedentary lifestyle or unhealthy diet. Nothing can substitute a diet rich in fruits and vegetables, omega-3 fats, fibre and protein and low in trans fats, refined

carbohydrates or added sugars, but medication can certainly help many people.

Following his diagnosis, Zoccole went to diabetes school at St. Michael's Hospital. For two days, he sat in a class learning how to read food labels, how different foods can affect your blood glucose levels and how to manage diabetes. This education was the beginning of a series of major lifestyle changes.

A small army of healthcare professionals has helped along the way. Zoccole now sees his diabetes doctor, heart specialist and kidney doctor every six months. And his HIV doc acts as his primary care physician. Zoccole makes sure that all of his doctors know what's going on with him—when he starts taking a new drug, when he stops a drug, and so on.

Zoccole used his experience with antiretroviral therapy to guide him with his diabetes management. He points out that when you're not feeling well or when you start a new treatment, you assume that this is how it's going to be forever, but that's not necessarily the case. For example, Zoccole experienced gastrointestinal problems during the first year of taking antiretroviral therapy, but when his doctor switched one of his meds, those side effects disappeared and never returned. "It was a process of trial and error," he says. He took a similar approach to managing his diabetes.

Zoccole now checks his blood sugar level at the same time every morning. Because alcohol can affect your blood sugar, when first diagnosed he cut back on drinking, and six years ago he cut out wine, beer, anything alcoholic, completely. "I used to be a couch potato," he says. But that changed, too. He started eating a light supper after work and then heading out for a two-hour walk. He now exercises as often as he can and gets plenty of sleep.

Zoccole also tries to eat healthy—lots of vegetables, brown bread and rice instead of white. He acknowledges that it can be hard to break old habits, but it helped that growing up in Northwestern Ontario his traditional diet included wild game (goose, rabbit and partridge), wild rice and fresh vegetables from the garden, so those healthier food choices were familiar to him.

Formerly a pack-a-day smoker, Zoccole has also cut down to having just four puffs five times daily. While such changes can seem impossible at first, most of them get easier with time and practice. After landing in Melbourne, Australia, for the AIDS conference last summer, he noticed that his fellow smokers were jonesing for a smoke after the long journey, but he was OK. "Your body adjusts."

Change isn't always easy. It's one thing to know we should eat healthy, exercise and quit smoking, but it's another to do it. We are complex creatures and our behaviour is influenced by many factors, including our culture, age, gender and religion, as well as our individual values, beliefs and attitudes. I've found that the greatest success starts with increasing one's self-awareness. Before jumping into the nuts and bolts of serving sizes or grams of carbs, practicing mindfulness is one of the most powerful tools for making change.

Who Is at Risk?

TRADITIONAL RISK FACTORS

- having a parent or sibling who has diabetes
- being Aboriginal, Hispanic, South Asian, Asian or of African descent
- having metabolic syndrome – three of the following symptoms: high blood pressure, high fasting blood sugar, large waist size (greater than 102 cm for men, 88 cm for women), high LDL or "bad" cholesterol and triglyceride levels, and low HDL or "good" cholesterol levels
- having sleep apnea
- being diagnosed with pre-diabetes or insulin resistance
- being over the age of 40
- being overweight, especially if you carry extra weight around your waist
- having polycystic ovary syndrome (PCOS)
- lower socio-economic status

HIV-SPECIFIC RISK FACTORS

- HIV infection, especially when accompanied by a low CD4 count and a high viral load
- certain older HIV meds – some nukes, such as d4T (stavudine, Zerit) and ddI (didanosine, Videx EC) and some protease inhibitors, such as indinavir (Crixivan) and nelfinavir (Viracept)
- being coinfecting with HIV and hepatitis C, which makes people over the age of 40 far more likely to develop diabetes than people who are mono-infected with HIV

What's Your Type?

Type 1 diabetes usually starts during childhood or adolescence. Your body makes little or no insulin, the hormone needed to carry blood glucose to your cells and fuel them with the energy they need. This causes high blood sugar (or blood glucose) levels.

Type 2 diabetes, which typically develops during adulthood, is by far the most common kind of diabetes among the general population and among

people living with HIV, accounting for an estimated 90% of cases. Your body produces insulin, but doesn't use it properly. This is called insulin resistance and blood sugar levels rise as a result.

Gestational diabetes develops during pregnancy. Blood sugar levels usually return to normal after the baby is born.

Pre-diabetes is when your blood sugar levels are higher than normal but not high enough to be considered diabetes. The condition can be reversed but nearly 50 percent of people who have it go on to develop type 2 diabetes.

Seek support

Dealing with life's challenges and stresses is something everyone faces but it can take its toll. Seek emotional and psychological support from a peer support group or a counsellor. Sharing your experiences with others can provide an opportunity to swap tips, relieve stress and prevent burn-out as you learn to manage your condition.

Acknowledge the barriers

Deciding what needs to be changed to improve your health requires honest reflection about your situation and prioritizing what can reasonably be tackled. What might get in the way of you achieving your goal? What could help you overcome those challenges?

Start small

Research shows that people are more likely to be successful in making changes when they don't try to make too many at once. Taking on one, at most two, big goals will likely be more successful than if you try to tackle three or more all at once. One easy way to get a sense of whether or not you're likely to be successful at achieving your identified goal is to ask yourself: How confident am I that I can achieve this goal? Rate your confidence on a scale from 1 to 10. If you can't rate yourself as an 8 or a 9, set that goal aside for now and consider trying another one.

Set SMART goals

Change doesn't just happen on its own; it needs a clear plan to be realized. Simply saying, "I want to start eating better" will likely yield little. This is where SMART goals can help. The acronym stands for Specific (the objective is clearly defined, so I know

exactly what I want to accomplish), Measurable (I will be able to evaluate whether or not I have met the goal), Attainable and Realistic (the action plan is achievable and not overly optimistic) and Timely (the timeframe is reasonable).

By taking the vague desire "I want to eat better" and applying these criteria, a SMART goal might look like this: "Starting next Monday, I will eat four additional servings of vegetables each week." It's specific (my goal is to increase my vegetable intake), measurable (four additional servings), attainable and realistic (I know I am capable of eating more vegetables) and timely (starting next Monday).

While the concepts of specific, measurable and timely are relatively straightforward, what is attainable and realistic will vary from person to person. This is where honest reflection, identifying barriers and rating how confident you feel about your objective come into play. There is no right or wrong goal, only what is right for you.

By choosing easier-to-obtain goals, you'll be more likely to achieve them. Once you've achieved a goal and kept it up for three to four weeks, layer on another, and then another. Achieving a larger, longer-term goal is easy when it's broken down into smaller, more manageable steps.

Using this approach, most people feel a sense of pride and accomplishment, which can motivate you to take things to the next level. As the saying goes, success breeds success. "You do see the benefits and rewards after a while," Zoccole says. "As my doctor said, I'm guarding my health." ✚

Doug Cook is a registered dietitian and holistic nutritionist and co-author of *Nutrition for Canadians for Dummies*. www.doucookrd.com

BEFORE

jumping into the nuts and bolts of serving sizes or grams of carbs, practicing mindfulness is one of the most powerful tools for making change.



Aches and Pains

An estimated 1 in 5 Canadians suffers from chronic pain due to illness or injury—and that number is likely higher among people living with HIV. Three experts give their best advice on how to cope with persistent pain.

INTERVIEWS BY JENNIFER MCPHEE AND DEBBIE KOENIG

GLORIA TREMBLAY

Living with HIV since 2003
Regina

I've had pain throughout my body for more than a decade. When it started I would wake up doubled over in pain. I also have numbness in my feet, legs and arms; sometimes it feels like my feet are between someone's teeth. I haven't been given a diagnosis for most of my pain but an X-ray confirmed that I have arthritis in my knee. At 71, I am the oldest in my HIV support group and seem to be the only one living with chronic pain. Is it due to the HIV, my HIV meds or aging? No one knows for sure.

The pain affects my activities but it hasn't stopped me from being active. I used to walk for miles; now I walk

just a couple of blocks at a time with my Nordic walking sticks. I used to dance—the mambo, cha-cha, *paso doble*, tango. Unfortunately, I can't dance anymore.

My doctor suggested I take up swimming, so now I swim for an hour every other day. It works beautifully: Swimming improves the pain, diminishes the tingling in my feet and reduces the swelling in my knee by 50 percent. My clothing now fits more loosely, too, which is a bonus. And because I have less pain, I sleep much better.

I think that my pig-headedness helps me. I won't give up. If I'm getting a pot or pan out of a low drawer and I'm unable to get up, I say to myself, "You son of a gun, you better follow this woman," and then I pull myself

back up. My advice to others is, if you don't have a pig head, borrow one!

As people living with HIV, our bodies don't always respond well to stress. So, having fun and laughing are important, too. I'll watch standup comedians for hours on end and laugh until my ribs ache.

I'm not complaining. There are people my age who don't have HIV and are living in nursing homes. I live independently, I have four volunteer jobs and I have season tickets to Regina's Globe Theatre. I share my horror story with nurses and whomever I'm invited to share with. It can be tough and sometimes I feel like quitting the fight but I count my blessings. I still enjoy life to the fullest surrounded by my family and friends.

NOLI CATAPANG

Registered acupuncturist
Catapang Clinic and
Positive Living BC
Vancouver

Most of my acupuncture clients who are HIV positive come to me for chronic pain. Many are dealing with neurological pain, which typically takes the form of numbness or a burning sensation in the hands and feet, or chronic headaches.

Long-term pain not only hurts you physically but it also drains the body's resources and can be exhausting. These problems are compounded by the fact that pain is invisible and most people don't talk about what they're going through, so they don't get a lot of sympathy because others don't realize that they're hurting. This can be isolating and demoralizing. That's the harsh reality of living with chronic pain.

As a practitioner of Traditional Chinese Medicine (TCM includes acupuncture as well as herbs, massage and other therapies), I believe in the presence of chi (energy flow) and I look at why a patient's chi is less than ideal. Pain and other symptoms can be alleviated when a person's chi is balanced and moving more strongly through the body. If I can balance a person's chi and get it moving more smoothly and strongly through the body, I can alleviate their symptoms.

When treating a new client, I start by taking a detailed account of their overall health, past and present. I take their pulse and examine their tongue. Based on this, I deduce how their body is functioning and how well their chi is flowing—where it is strong and where it's weak or poorly regulated. Then I select acupuncture points that will help rectify the situation. Once I've placed needles, I like to leave them there for at least 20 minutes. However, some people with chronic pain can't comfortably sit or lay still for that long, so the treatment is adapted to each individual.

One of my goals is to reduce a person's need for pain medication, as many people with HIV are already taking other meds. If I can control their pain with acupuncture, they can

stop taking prescription and over-the-counter pain control drugs, which is good for the body and the pocketbook!

Everyone wants to know how long it will take for the pain to go away. We've all heard stories of people who experience dramatic gains immediately, but, unfortunately, that is not the norm. Alleviating a person's symptoms is typically a process, not an event.

Most of the people who come to see me have already struggled with their pain for months, years, even decades. I can often get a person to a point where they no longer need to take pain medication and they see me only about four times a year. It takes time to get there, but it can certainly be done.

WENDY WOBESER

Infectious diseases specialist
Hotel Dieu Hospital
Kingston, Ontario

In my clinical HIV experience, pain often relates to a prior injury or osteoarthritis. While peripheral neuropathy can be debilitatingly painful for many people, for some people painful peripheral neuropathy appears to "burn out" and does not require pain therapy.

Chronic pain can put stress on all aspects of a person's life—your activities, spirit and mood, your relationships and ability to work. Unfortunately, there's no easy fix. A thorough evaluation of the type of pain and, if possible, what's causing it is a critical component of managing it. The pain management strategy should be guided by whether the source of the pain is from a cancer (malignant) or not (non-malignant).

Although medical treatments, such as over-the-counter and prescription medications, can be valuable for managing pain and minimizing the impact it has on your life, they may not be the most important part. Robust coping skills and mind-body techniques can make a big difference. The people I've met who are best able to cope with pain work hard to minimize its impact on their day-to-day lives. In many instances, this means modifying one's expectations and actively pursuing activities that bring a sense of

WHERE DOES IT HURT?

Keeping a pain diary can help you track your symptoms and how you're feeling day to day. Where is the pain? How bad is it? How is it affecting your mood, sleep and activities? What brings you relief? What makes it worse? This can help you and your healthcare providers monitor your pain and notice any patterns.

well-being, whether it's exercising or making music or engaging socially—whatever works for you. There are also peer support programs that can help break a person's sense of isolation and connect them to resources and tools that help them cope while trying to live life as fully as possible.

A number of clinicians believe in the power of mindfulness as an important component of an effective strategy. Mindfulness teaches you to become conscious of what you're thinking and feeling in the present moment without judging it. The theory is that this might interrupt feelings of stress, anxiety and depression that can exacerbate pain. I believe that practicing mindfulness is most effective when combined with other strategies, such as physical therapy.

For people who have addictions, managing the addiction and dealing with underlying mental health issues with the help of a knowledgeable expert is also critical. That's because underlying mental health issues can heighten pain and vice versa, creating a vicious circle.

Finally, I caution patients against the long-term use of narcotics—such as oxycodone (OxyContin, also in Percocet), Tylenol 3 and 4, Demerol—and against increasing their dose, as these drugs can cause serious side effects and be extremely addictive. +

For a listing of pain clinics in Canada, visit The Canadian Pain Coalition at canadianpaincoalition.ca



Of Hope and Sickness, 2013

Picture This

Shan Kelley's provocative art reframes sickness and stigma.

BY JENNIFER MCPHEE

When I call mixed media artist Shan Kelley, 37, one evening, at his home in Montreal, he apologetically asks to reschedule our interview because his 16-month-old daughter has a cold and is up past her bedtime. Later, he admits that prior to his HIV diagnosis five years ago he hadn't envisioned having a child. He actually surprised himself by suddenly asking the doctor who diagnosed him whether he could still father a child. "I think what I was really asking was, 'Will I be able to go on?'" he says.

Kelley's art often combines storytelling and photography and is almost always autobiographical and intensely personal. His piece *Of Hope and Sickness* consists of two photographs with passages of writing explaining their significance. Kelley's mother snapped

one of the photos just days before her son's diagnosis. Kelley is sick, lying on his mother's couch, as he did for several weeks, feeling exhausted and incapacitated by an illness that had not yet been named. He is sleeping under a white duvet, with his head resting on a white pillow. Four years later, Kelley took the other photo upon noticing his newborn daughter lying in the same position, on the same couch, also under a white blanket, with her head resting on a white pillow.

Kelley explains that watching his daughter sleep made him contemplate the innocence of that moment and "a passage in life that I never thought I would live to see, a moment I imagined would never be possible given my HIV diagnosis." Capturing this dichotomy between illness, on the one hand, and

hope and innocence, on the other, "serves to frame my entire relationship with my own mortality, perseverance and hope."

Your work has become much more personal over the last several years.

Is this because of your HIV diagnosis?

Yes, partly. My post-diagnosis reality was unfamiliar and frightening but it also became a catalyst for tremendous growth and discovery. I've overcome the fear of producing work that is largely autobiographical. I'm completely unashamed and open about being HIV positive. And I find that by using my own voice in my work, I can introduce an empowering, nuanced counter-narrative to this era in which privacy and agency remain so threatened and tenuous. If I can't control my

own privacy, then perhaps I can mitigate the messaging around HIV and frame it in my own words.

You write that you felt “naked, exposed and under oppressive surveillance” after your diagnosis, as if your sexuality and private life had become fair game for scrutiny. Can you explain what you mean?

In my life, I’ve had two great points of intense vulnerability: recently, when my father died and when I was first diagnosed. The healthcare system wanted to understand and trace how I became HIV positive, which proved impossible, as I couldn’t pinpoint a person, place or time. Healthcare workers wanted to dissect my lifestyle, behaviour, choices and promiscuity. They not only wanted answers but I think they perhaps also wanted my repentance. The elephant in the room is that HIV brings to light human behaviours that are uncomfortable for people to acknowledge, much less accept. But I’m unapologetic about who I am.

What does it feel like to experience stigma?

I love meeting people who are uncomfortable with HIV. I’ve experienced some difficult situations, particularly when my partner’s circle of friends found out about my status and wanted to “protect” her when we first started dating. One person said outright that he would never feel

“I’m not interested in transmitting anything that isn’t based on truthfulness.”

safe with me near his children (even though he didn’t have any at the time). It’s become easier for me to stay composed during such incidents because I understand that judgment and fear come from ignorance and misunderstanding. These negative stigmatizing views are regrettably still often reinforced by media and outdated ideas of an HIV bogeyman.

I really like *Postcards*. What were you trying to explore with it?

Thank you. *Postcards* is a series of printed aluminium signs placed in



Growing Concern, 2013

public spaces. The text on each sign describes a distinctly uncomfortable negotiation of sexuality and HIV. I wanted to explore how our physical spaces and geographic landscapes are also charged with a hidden emotional landscape. I might feel a sense of lightness when I pass a park where I shared a fantastic kiss, or conversely, a sense of unresolved weight when I pass a corner where I once received bad news. My hope was to interrupt public spaces by introducing some of my very private moments that occurred there.

Postcards 1 and 2



Can you talk a bit about your decision to have a child?

I became a father post-diagnosis. Because of my undetectable viral load, I had no trepidation about creating a child without in-vitro sperm washing and without subjecting my HIV-negative partner to PrEP (pre-exposure prophylaxis). Yet this decision was unfortunately met with incredible apprehension and resistance from people I had expected to support us—from veteran HIV practitioners to medical support staff. Everyone seemed to tow the fear, to the point of absurdity. On more than one occasion, my partner was even told by health professionals to reconsider our relationship altogether.

Immediately after our daughter was born, many people congratulated us and celebrated her negative status as a great achievement. As if she would be worth less to us if she had been born HIV positive. Would we then have failed as parents, as humans?

In *Growing Concern*, there's a photo of a baby in a crib with the words "What Will You Teach Your Children about AIDS?" on the wall beside her. How will you teach your child about HIV?

I'm raising a radical. There will be no "papa is sick"—type discussions, but there may eventually be some "papa is sick of apathy and is working on dismantling the AIDS industrial complex." My daughter will be like a stateless warrior and one day she will raise her sword to fight as well. I will give my child everything I have, no less. I'm not interested in transmitting anything that isn't based on truthfulness, and I hope that my transparency will guide her to form a unique understanding of the world through the lens of a person living with HIV. +

Shan Kelley lives with his partner and daughter in Montreal. To see more of Kelley's work, visit shankelley.com

Jennifer McPhee is a freelance writer whose work has appeared in *Chatelaine*, *The Globe and Mail*, *Childview* and numerous other publications.



Wingspan

My name is Claudette Cardinal and I have been living with HIV for almost 20 years. Originally from Edmonton, I now live in West Vancouver. I am Cree. I am a grandmother six times over. In the spring of 2010, a leadership training for HIV-positive women started me on my path of transformation.

Egg: germ of a new life. I first heard about Positive Leadership Development Institute training through my local AIDS service organization, the Positive Women's Network. My hope was to find out who I was as a leader.

Caterpillar: a time of growth. The training was challenging, but the camaraderie and sense of oneness among the group inspired me. It felt very safe. I could see right away how we were all leaders by the way we were networking and helping one another. Having that support upon completing the training made me feel like I was coming out of my cocoon and flourishing.

Chrysalis: a time of change. Since then, I've taken three more trainings—to explore my leadership potential, improve my communication skills and learn about board governance. These enabled me to find out who I really am.

Butterfly: metamorphosis completed. Now an Elder, I sit on the board of directors for Positive Living BC and I am a peer research assistant for a national HIV study. My next step is to go back to school. I try to empower as many women as I can in my daily life.

Upon completing the training, I went on a wellness retreat for positive Aboriginal women. While walking along the banks of the Chehalis River, we saw this butterfly. Like these creatures, we all have the power within us to grow. Even if you don't think you do, it's there—you can transform, spread your wings and take flight. +

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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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If you have a story idea or photo for the next issue, write to us at

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and tell us what's on your mind. We're happy to offer anonymity to anyone who wants it.



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