

THE POSITIVE SIDE

HEALTH INFORMATION & VIEWS

SUMMER 2015 VOLUME 17 ISSUE 2

What poz youth want
you to know

Straight men
living with HIV

Adherence all-stars

The art of
Jessica
Whitbread

ONWARDS & UPWARDS

The unstoppable
Gloria Tremblay

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HIV disclosure:
UPDATED LEGAL INFORMATION
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healthy pregn
if you are HIV pos



Treat Me Right
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EDITOR'S LETTER

This summer issue of *The Positive Side* takes a dive into the depths of living with HIV. If you want to dip your toes in first, or if you're the type who prefers lounging dockside, by all means start with nutritionist Doug Cook's suggestions for healthy, hydrating summer drinks. If you want to jump right in, check out "The Engagement Cascade," which explains how a group of people with HIV reimagined the treatment cascade to better reflect their experiences.

Visual AIDS contributor André Quenneville names another strong thematic current. Capturing a celebratory moment on the shores of the Atlantic Ocean, he reminds us to look beyond the obvious and attend closely to the myriad experiences of living with and triumphing over HIV.

It is important to look beyond the surface. Our cover story reveals what lies beneath Gloria Tremblay's exuberant smile: heartbreak and betrayal, coupled with an overriding personal drive to set things right—not just for herself but for others living with HIV, too. In "Adherence All-Stars," we meet a group of Albertans with HIV who describe their lifestyles as "chaotic" but who have mastered the art of adherence so well that they're taking their message on the road.

Also in this issue: Ask the Experts breaks down a complex topic that's been the subject of much discussion: the role of inflammation in HIV disease. Chatty CATIE introduces four young people living with HIV. Guess what? They're doing just fine, thank you. In "In Search of the Invisible Man" CATIE staffer Sophie Wertheimer goes in search of a rare epidemiological phenomenon: the straight man living with HIV. And in Art Posi+ive, we get reacquainted with Jessica Whitbread, a young queer artist whose main creation is community. Try hanging that on your wall!

Whether you're at the lake, reading *The Positive Side* curled up in a hammock, or sitting on a patio in the city, take time this summer to raise a tall beverage, hopefully bursting with antioxidants—to your health!

—Darien Taylor

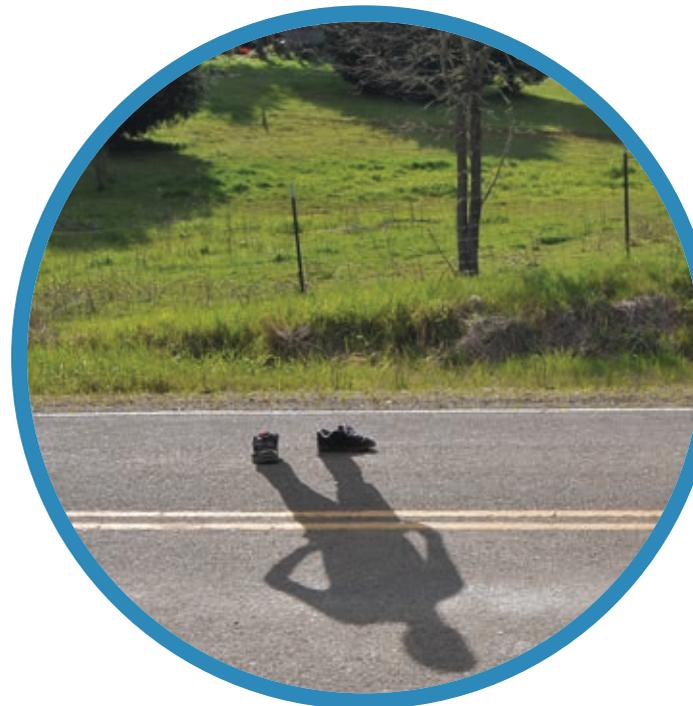
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Gloria Tremblay,
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Well, well, well...

Peter Carlyle-Gordge has the scoop on HIV wellness programs across Canada.

Taking your meds is only part of the equation when it comes to living well with HIV. Here we look briefly at some programs across the country that help you maintain the joy in living, share your wisdom, make new friends, keep your body moving and get your creative juices flowing.



Yoga Classes for Men

Want to increase your flexibility? Circulation? Peace of mind? HIM (Health Initiative for Men) offers weekly drop-in yoga classes for men in Vancouver and Surrey, BC. "Positive guys, of course, are welcome," says program manager Darren Usher. "Lots of positive guys enjoy our yoga classes but we don't know exactly how many, as we never ask. The main feedback we get from them is that they love being in a group where their status is never an issue."

The Vancouver location attracts between 30 and 40 guys per class. And the new Surrey classes are already drawing about 10 guys each week. Usher, who is also one of the program's loyal yogis, gives his personal stamp of approval: "As I grow older, I feel that my flexibility, strength and balance are all very important, so I really like yoga because it gives me a bit of all three."

Bring your own yoga mat and towel. Sessions are pay-what-you-can (most people give \$5 to \$10).

For more info, visit checkhimout.ca/yoga-with-him

African, Caribbean and Black Straight Men's Group

In the Waterloo, Ontario region, more than half of the people who tested positive for HIV in the past five years were infected through heterosexual contact. Responding to the needs of this community, the AIDS Committee of Cambridge, Kitchener, Waterloo and Area (ACCKWA) is offering a space where black straight men with HIV can meet and talk with peers. The monthly men's group offers a chance for participants to express their feelings and connect with others going through similar experiences.

For more info, contact Priscilla at acstrategy@acckwa.com or 519.570.3687, ext. 309

Coffee Talk

Nine Circles Community Health Centre's Coffee Talk in Winnipeg offers people a chance to socialize and learn more about all things HIV. The hour-long evening sessions, run by coordinators Rosa Colavito-Palao and Sandra Robinson, are for anyone with

HIV—whether you're a newbie or a veteran. "It's a safe and confidential space where people can come and talk about anything from HIV meds and side effects to diet, disclosure and housing problems," says Colavito-Palao. "Our aim is to break people's isolation and provide good information. Sometimes we bring in outside experts to lead the discussion."

To find out more, visit ninecircles.ca or call 204.940.6001



Circle of Courage

AIDS Programs South Saskatchewan's Circle of Courage is a peer-led support group in Regina that focuses on the information and support needs of HIV-positive women with children and those who are considering pregnancy. Through education and by sharing personal experiences, the goal is for participants to become mentors to other HIV-positive women in similar situations. "Many of the women who participate in the Circle are Cree. We focus on activities that build strong social and cultural ties," says coordinator Krista Shore. Last year participants made traditional ribbon skirts and shirts for ceremonial events. They have also shown interest in learning about drum making and drum ceremonies in the future.

For more info, visit
aidsprogramssouthsask.com/support-groups.html
or call 306.924.8420



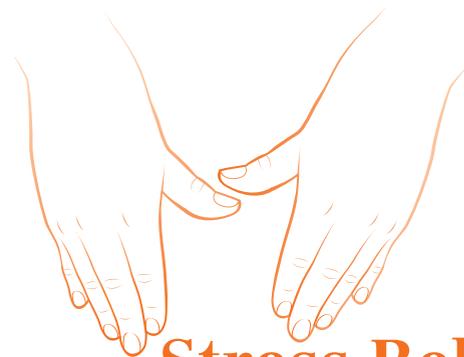
Journée Liaisons positives

Journée is a pan-Quebecois gathering of women living with HIV. Each year the retreat takes place in a new location, with the objective of attracting new women and giving regulars an opportunity to get away and spread their wings.

The retreat takes place in a festive atmosphere, where participants receive meals, presents and door prizes. They can participate in organized activities—such as yoga, volleyball and personal growth workshops—and take sightseeing tours. A former *Journée* organizer notes that some women arrive with a big weight on their shoulders, but, she says, "I have never seen one woman leave with her back bent."

The 24th *Journée Liaisons positives* will take place September 12, 2015, at Cap-St-Jacques, on the west tip of the Island of Montreal. This event is held in French.

For more info, contact Patricia Connolly at
comitepasf@yahoo.com **or 514.345.4931, ext. 5444**



Stress Relief

As it goes without saying that living with HIV can be stressful, a free massage might be just what the doctor ordered. The AIDS Coalition of Nova Scotia in Halifax offers a volunteer-run massage service that has been going strong for more than a decade. Close to 50 clients make regular use of it. "This has been one of our most successful programs," says program coordinator Michelle Johnson. "It helps people relax and relieves stress as well as their physical aches and pains. Our massage therapist individualizes each treatment. She uses a variety of techniques and may use a heating pad or ice packs, if that's indicated. And clients can choose the music that they want to listen to as they relax."

To book a 60-minute massage, call 902.425.4882

Winnipegger Peter Carlyle-Gordge is a former writer for *Macleans*, *Time Canada* and *The Financial Post*. He has also written for most major newspapers and magazines in Canada. In the 1980s he was president of the Village Clinic (now Nine Circles Community Health Centre).



Talking 'Bout My Generation

What HIV-positive youth want you to know.

INTERVIEWS BY RONNILYN PUSTIL



ASHLEY ROSE MURPHY, 17
Student and volunteer speaker
Diagnosed with HIV at
6 weeks old
Ajax, Ontario

When I was diagnosed at six weeks of age, I had PCP (*pneumocystis pneumonia*) and was in respiratory distress.

I was always told by my adoptive parents (they adopted me when I was three) that I had a bug but not the name of it. When I was seven they told me the name of it and said I should keep it a secret. I didn't think I should have to because I hadn't done anything wrong, so I just told people. I was uninvited to birthday parties, had neighbours say I couldn't play with their kids, had some friends' parents (just last year) give me disposable plates, cups and cutlery. And I've had a bit of online bullying, too. But I keep going and it's getting better.

I started public speaking at age 10, at an HIV conference, then at galas, on TV and now I do motivational speaking. I never intended to be a motivational speaker, but I started to see that my words could make people with HIV feel less alone. I just want to make a difference and decrease the stigma, educate people.

HIV-positive youth are sometimes left out of the dialogue. But we are out here and we are fighting for the same things: zero discrimination, access to meds, a cure, love and acceptance. **Youth who are born with HIV have a different reality.** We are not angry with ourselves, as we had no say in the matter. No one I know is angry with their mom for passing it to them—we know it was not intentional. We have never known anything else; we have always lived with HIV.

My mom says the teen years are hard enough without having to deal with HIV but I like to focus on the good things in my life that have come to me *because* I'm HIV positive: my big adoptive family, summer camp and clinic friends, travelling and interesting things I have done. If you dwell on the negative stuff, it brings you down. I choose to take the stuff in my life that others see as a problem and turn it into a strength. In my speeches I often say, "Rock your differences, own them and be you." I find a lot of peace and happiness from doing that.

MICHAEL SCHNEIDER, 30
Program coordinator, Positive Youth Outreach (PYO)
Diagnosed with HIV at 25
Toronto

I run the PYO program at ACT (the AIDS Committee of Toronto), for people ages 16 to 29. (It's our 25th anniversary!) I spoke with our youth discussion group to ask them what they would like the HIV-positive community to know about poz youth. The group is made up of diverse men and women who are straight, gay and trans, and range in age from 20 to 28.

Many young people with HIV today feel separate and segregated from the HIV community. It isn't like when HIV first came around over 30 years ago, with people rallying together, supporting and advocating for one another. These days, people seem to be more grouped together either by age or race within their communities.

We hear a lot of "you're young and you didn't go through what we went through," as though younger people with HIV haven't earned their dues and are riding on the coattails of all those who came before us. What people tend to forget is that some youth were born with HIV and have been living with it for 20 years or longer, resulting in an entirely new experience and identity. Due to this lack of understanding, HIV-positive youth sometimes feel

that they are looked upon as pariahs and feel stigmatized by HIV-negative people as well as older people who are living with HIV (PHAs).



Because we're from a different generation, we view HIV differently. We think of it as a manageable condition and do not identify ourselves primarily as HIV positive. Our identities are those of “everyday people”—who go to school, have jobs and create meaningful relationships. We are more likely to discuss music, our astrological signs and future aspirations than talk about living with HIV to strangers. We are less likely to wear our HIV status like a name tag or label.

We learned about HIV in school, we want to be healthy and we know to go on medication, but because there's more of a disconnect with the virus, the effects of not taking the meds seem far in the future. We're thinking about paying off debt, travelling, going to school, dating and so on. And this impacts our adherence. The benefits of the new one-pill-a-day HIV meds are truly felt by us. We are grateful for that.

RORY S., 27

Hotel admin and music teacher
Diagnosed with HIV at 21
Calgary

On a day-to-day basis, HIV doesn't even enter my mind because the treatments are so awesome. If it wasn't for my YouTube channel (TheJelloSlapper) I doubt that I'd really consider it an issue. (My video blog follows me, a gay man living with HIV, through my weekly struggles, victories and adventures.)

I think that younger gay men like myself are incredibly fortunate to

be this “second generation” of PHAs. Having the resources and treatments developed by those who came before us in the past 20 years has allowed us to focus more on social issues such as stigma. **HIV stigma is the number 1 issue that I struggle with.**



I live in a city that isn't known for being the most progressive when it comes to HIV. Many younger PHAs I know feel the need to hide their status for fear of being rejected by those who are not aware of the benefits of treatment.

But, thankfully, PrEP (pre-exposure prophylaxis) and treatments that allow an HIV-positive individual to have an undetectable viral load have already started to revolutionize the way PHAs are looked at and treated by the general public. Over the past two years I have noticed a huge increase in positive-friendly interactions with gay men. Undetectable statuses and PrEP have taken much of the fear away from HIV-negative individuals, allowing them to form strong and healthy relationships with PHAs.

That being said, disclosing my status is never easy. However, as I get older, and the people around me learn more about HIV, it does become less cumbersome.

JON CLAGGETT, 30

Advertising consultant
Diagnosed with HIV at 28
Regina

First of all, I'm OK! Being diagnosed was probably the worst part of the entire experience. From there, every day got a little bit better, and as my health improved, I felt better about

the situation. Finding out that I tested positive was devastating but I read a lot about HIV and made a conscious effort to get as healthy as possible as fast as possible.

When I was diagnosed, I had a low CD4 count and a high viral load. It didn't take long before my CD4s were in the high 1,200s and in six months my viral load was undetectable. Besides having to remember to take one pill a day, my life is virtually unaffected by the disease. I've been fortunate enough to fall in love with someone who is negative and our relationship is just fine.

That said, this is what I think people need to know: End the stigma! The hardest part about being diagnosed was the feeling that I had done something terribly wrong or that I deserved this. I felt that as a gay man I had become the worst possible stereotype. I felt that my social life, and subsequently my love life, would be brought to a screeching halt. Fast-forward a few months and none of this was true.

I had been in a committed relationship with someone who wasn't faithful, and that led me to have to deal with HIV for life. But the larger community still often views HIV as a disgusting thing—that the person who has the disease must be a bad person or they must have been a slut or a junkie.

Testing is what needs to be focused on. People need to feel good about getting tested; they need to feel confident that no matter the outcome they are going to be OK. **People need to not feel bad, or secretive, or dirty about getting tested but instead empowered by it.**

Knowing your status is a good thing. And even if you happen to be positive, you're still OK. You're still the same person you were before you were diagnosed. Get your meds and health in order and you'll be doing better than the average person.

Ending the misconception that HIV is a death sentence, or a gay thing or only for bad people is the next step. Educating people and bringing a positivity to testing while changing people's opinions about HIV in general is where I think the HIV community needs to focus its efforts. +



Bouncing Back

Exuberant, outspoken and unapologetic, she redefines resiliency. Meet **Gloria Tremblay**.

BY JENNIFER MCPHEE

PHOTOGRAPHS BY GREG HUSZAR

Gloria Tremblay, 72, met her partner Larry through friends about a year after her husband of 38 years died of lung cancer. Unlike her emotionally abusive and controlling first husband, Larry seemed like a nice, uncomplicated man—a cattle farmer and pipeline worker who lived in rural Saskatchewan.

They dated for six months before having sex. Gloria wanted to use a condom that first night. “He looked at me and said, ‘What’s that? You don’t need that. I haven’t been with a woman for years and years.’”

So when Gloria’s lymph nodes grew to the size of the palm of her hand and she spent four months in and out of the hospital because of a mystery illness, doctors suspected multiple sclerosis, and then everything else but HIV.

Throughout the ordeal, Larry dutifully drove her to medical appointments but didn’t seem overly concerned. “He just acted like a normal man from my generation,” Gloria says. “He believed that if you don’t have a cast around your head, you’re not sick.”

Then, one day in April 2003, she happened to see a different doctor at her usual medical clinic. When the doctor noticed Larry sitting in the waiting room with her, he asked Gloria how she knew Larry, and then immediately

ordered more blood tests. He didn’t tell Gloria until later that he had diagnosed Larry with HIV four years earlier.

When the doctor informed her she was HIV positive, Gloria says it was so unexpected, it was like being smacked across the face with a sledgehammer. “I didn’t fit the profile,” she says. “I got married when I was 18 and stayed married to the same man for 38 years. I never picked up a guy in a bar. I was never a drug addict.”

Her diagnosis marked the beginning of the most painful period in Gloria’s already difficult life. She would soon feel so desperately abandoned and alone in her small rural town that she would come close to taking her own life.

At first, Gloria was angry at Larry but she was too sick to express it. They stayed together and she slowly began to put the pieces of the puzzle together. Larry, a recovering alcoholic, revealed that he used to get so falling-down drunk that he would wake up beside women he didn’t recognize.

By the time Gloria was diagnosed, Larry was probably equally sick but refused to admit it and wouldn’t take HIV medication until Gloria

dragged him to the clinic. Even after that, he didn’t follow the doctors’ orders properly.

“I kept asking him, ‘Why did you do that to me!? Why didn’t you tell me? Why did you tell me to not use a condom?’ He kept saying, ‘I work hard. I’m on my feet. You’re on your feet. We’re not sick, what’s your f**king problem?’”

They stopped living together several years later when Larry started drinking again. One night, after they had parted ways, he told his drinking buddies that Gloria had given him HIV. It was an act that ruined Gloria’s relatively pleasant life in Canada’s Bible belt.

Until then, Gloria had been a well-loved member of the community, an enthusiastic volunteer who flipped burgers at the local hockey rink, peeled mountains of carrots and potatoes for weddings and funerals at local churches, and delivered meals to the town’s seniors.

One week after Larry’s false revelation, everybody in town knew that she was HIV positive. The phone stopped ringing completely. “Out there, HIV is not a good word,” she says. “The whole town started hating me because of what he had told them. They didn’t



“If being out about my status and being a peer navigator can make life easier for even one person, then it’s worth it.”

want me to serve food. They thought it would kill them, they thought I was that contagious.”

Gloria says she experienced so much discrimination and social alienation that she believed she would “die alone like a dog.” When it became too much to cope with, she hauled a rope and step ladder into the barn with the intention of committing suicide. She climbed the step ladder, before realizing she didn’t know how to tie the slip knot of the noose.

When she turned around, she saw Larry’s cows gathering around the ladder. Ignoring them, she climbed down and sat on the ground to work on getting the knot right. She looked up, picturing her lifeless body hanging from the rope, and imagined the pain it would cause her daughter and elderly mother.

“I bawled and bawled,” she says, crying over the phone as she remembers that day. “And the cows started licking my face. It was like they were saying ‘don’t do it.’ I sat there for two or three hours. I didn’t know how to pick myself up. But when I got out of there, I thought, I’m going to live and I’m going to do something with my life.”

Larry died from AIDS in 2009. Before he died, he was hospitalized after a

serious car accident on the Trans-Canada Highway. While he was in the hospital, his doctors discovered a massive tumour in his brain. Gloria then learned that the brain tumour probably explained the way he had dealt (or not dealt) with his HIV diagnosis as well as hers. It also explained other weird and out-of-character behaviour—like the way he accidentally and repeatedly drove the wrong way into oncoming traffic. When she had asked why he kept doing that, he would stare at her blankly.

This realization helped Gloria forgive him, and she spent the last months of his life caring for him in a nursing home that didn’t want him there because he had AIDS.

Two years after Larry’s death, Gloria made the decision to leave the small town where she continued to lead an almost friendless life. She asked her bargain-hunter son-in-law if he would look out for a home for her in Regina. Two hours later, he called her from the inside of a mobile home that was for sale. The home was old and decrepit but Gloria went for it. She used money that Larry had left her to completely transform it into her “prince home.”

Soon after Gloria moved, the General Hospital of Regina offered her a job in its peer mentorship program, which matches seasoned people living

with HIV with newly diagnosed individuals. Gloria saw this as her chance to do something good with her life.

The majority of people Gloria is matched with have had painful childhoods and tough lives. Many of them are addicted to alcohol and drugs. Getting her clients to trust her is something she enjoys. “I have met girls who were born in the back alley and raised in the back alley,” Gloria says. “They trust nobody. But they are smart in their own way. They are a lot smarter than I am. It’s fascinating to me how people learn the rules of this very rough world and learn to survive.”

By drawing on her own personal experiences and telling it like it is—without apologizing or mincing words—Gloria has acquired a reputation for being able to reach people. “I always say I don’t work for fame or money because it’s too late for that! I’m just trying to help people. If being out about my status and being a peer navigator can make life easier for even one person, then it’s worth it. And I do it more for myself than for them. It’s what’s keeping me alive.” +

Jennifer McPhee is a Toronto-based freelance writer who contributes regularly to *The Positive Side*. Her work has appeared in numerous publications, including *The Globe and Mail*, *Chatelaine* and *Childview*.



Healthy summer drinks
to quench your thirst.

Cheers!

BY DOUG COOK

Summertime and the living is easy, with hot weather, sunshine, patios and outdoor activities. Depending on how high the temperature and your activity level, you may need to pay extra attention to how well you're hydrated.

Normally the body easily balances its fluid requirements. Contrary to popular belief, you do not need to drink eight to 10 glasses of water per day. Our body provides us with an amazingly sophisticated hydration system: Water in equals water out, and you can meet your fluid needs by simply responding to your thirst.

There are times, however, when you may lose water faster than you can replace it. This can happen when you are active and sweating a lot, whether at work or play. Or you may have a health condition or be dealing with a medication side effect that requires you to drink extra.

Don't lose your cool. Staying hydrated during the hot summer months can be easy, tasty and healthy.

COCKTAILS & MOCKTAILS

Alcohol increases the amount of water you excrete by interfering with the hormone that regulates urination.

This effect isn't permanent but drinking alcohol can lead to dehydration, especially in warm weather. Consider limiting the amount of booze you drink and try to drink low-calorie fluids during and after happy hour.

Try a spritzer (wine with sparkling water), a shandy (beer mixed with lemonade or citrus-flavoured carbonated beverage) or a "mocktail" (a tall, frosty glass of juice and carbonated water, loaded with ice and slices of fruit).



SMOOTHIES

Smoothies are a great way to make your drinks nutritious. Try adding your favourite fruits and veggies to any of the following: water, cooled tea, milk or milk alternatives (hemp, almond or rice milk). You can also add protein powder or yogurt.

ICED TEAS

Whether you make them from black or green tea or from herbal teas like peppermint or rooibos, iced teas make a great-tasting summer drink, with antioxidants to boot.

KEFIR WATER & KOMBUCHA

Check your health food store for these refreshing drinks packed with probiotics—friendly bacteria with health-promoting properties. Like the bacteria naturally living in our gut, these microorganisms help us digest food, synthesize nutrients and keep bad gut bacteria in check. They also play a role in helping us to maintain a healthy immune system and a positive mood. Healthy gut=good mood! (Probiotics and probiotic-based foods have an extremely safe track record but because they are active bacteria cultures, check with your doctor before adding them to your diet.)

Staying hydrated during the summer is easy to do when you have delicious and nutritious bevies on hand. So go for variety. Trying something new will make for an enjoyable, thirst-quenching summer. +

Doug Cook is a registered dietitian and nutritionist. He is the coauthor of *Nutrition for Canadians for Dummies* and *The Complete Leaky Gut Health & Diet Book*.

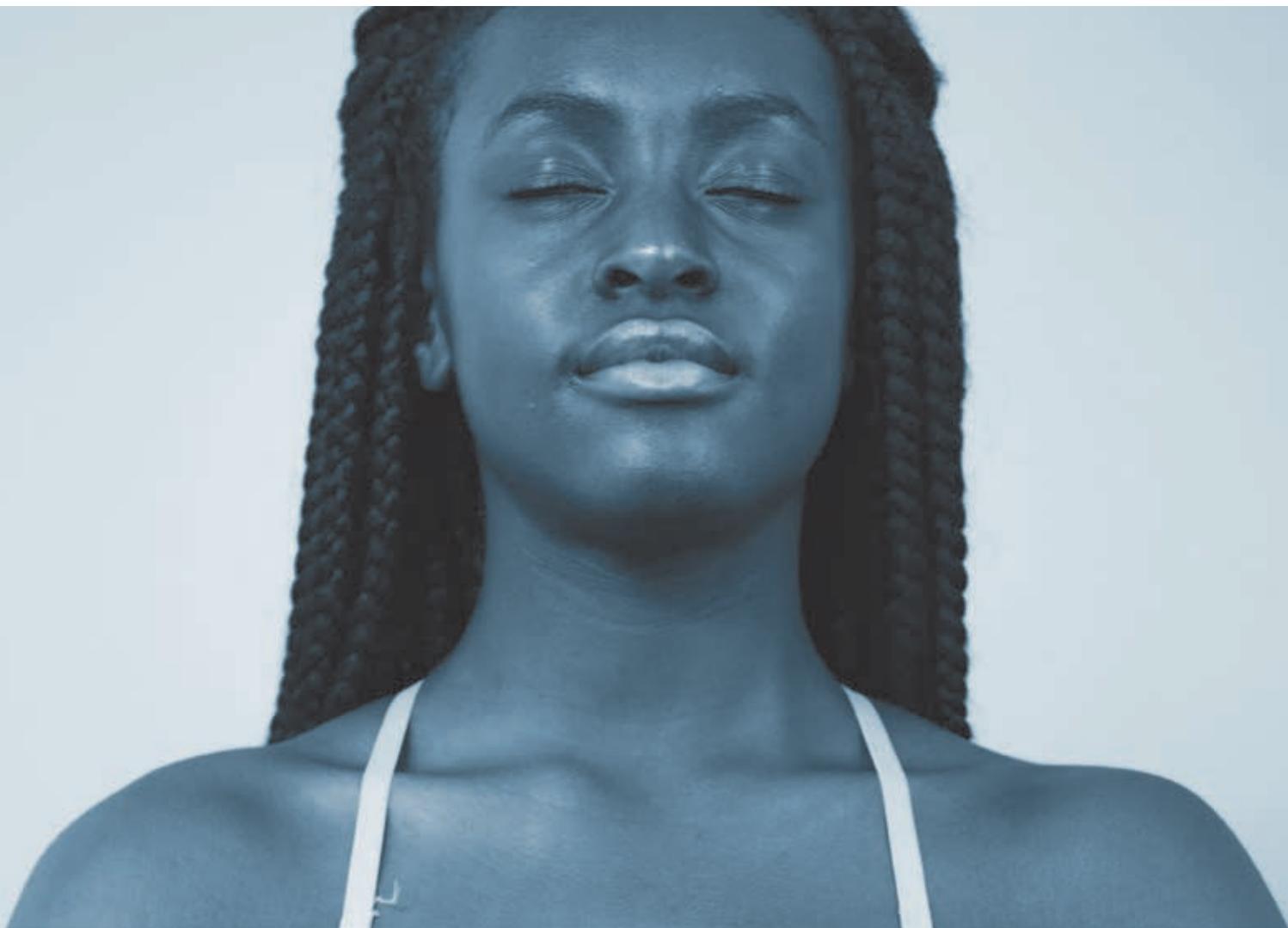


MIND —OVER— MATTER

If you practice mindfulness meditation, you may breathe a bit easier: Research reveals that it can be good for your mood, your mind and even your immune system.

BY SEAN HOSEIN AND DEBBIE KOENIG

There is lots of talk about mindfulness these days: mindful eating, mindful breathing, mindfulness meditation, even mindful leadership. The benefits might all sound a little too good to be true but it turns out that there's more to mindfulness than meets the eye.



WHAT IS MBCT?

Mindfulness-based cognitive therapy (MBCT) teaches us to become more conscious of what we're thinking and feeling in the present moment. As a result, we change our relationship with those thoughts and feelings. Dr. Evan Collins, a psychiatrist who leads MBCT groups in Toronto and has been living with HIV since the 1980s, says, "**Mindfulness is like surfing: We can't always control the waves of stress, depression or anxiety that life with HIV brings, but instead of letting them drag us under water we can learn to ride above them.**"

MBCT involves learning various meditation practices, many of which begin with focusing your attention on your breathing. As your attention wanders, you are encouraged to acknowledge your thoughts and feelings without judging them, and to redirect your attention back to your breathing. Eventually, you can start to explore your troubling feelings and thoughts more directly.

Therapy typically involves a series of weekly sessions in which participants learn about the effects of stress and emotions on their mind and body and how to use mindfulness to handle stressful situations.

A growing body of research has found that mindfulness can help improve the quality of life of people living with HIV. Studies have found that mindfulness-based cognitive therapy (MBCT) can quickly and significantly improve people's emotional and mental health. And the kicker is that it may raise CD4 counts, too.

THE RESEARCH

We know that stress, depression and anxiety can all affect the immune system and accelerate the progression of HIV infection. These conditions can also interfere with a person taking their HIV treatment every day. The flip side is that managing these conditions through interventions such as MBCT not only makes you feel better but may also help protect the immune system.

One large Canadian clinical trial examining the effects of mindfulness-based stress reduction on 117 men living with HIV showed that mindfulness was effective for developing a more helpful relationship to unwanted thoughts and emotions, including HIV-related worries. The men who participated in this study also reported less stress as well as increased hope, enthusiasm and life enjoyment. Another study found that mindfulness decreased the side effects of antiretroviral therapy (ART).

One of the most striking pieces of research into MBCT came out of a study of long-term survivors in Barcelona, Spain. All 40 study participants had been diagnosed with HIV prior to 1996 and had been on ART for at least five years. Half the participants attended MBCT classes for two and a half hours each week, over the course of eight weeks. These participants were also given CDs for guided mindfulness meditation, yoga and exercises. They were encouraged to practice for 45 minutes per day, six days a week. The other half (the control group) did not do mindfulness-based therapy.

THE STRIKING RESULTS

Depression levels dropped – Over the course of the study, rates of depression dropped significantly among the participants who received MBCT. At the start of the study, researchers found that about four out of every five participants showed signs of depression. By week 20, only one in five participants who had received MBCT experienced symptoms of depression—and the intensity of their depression was graded by the research team as mostly “minimal.” By contrast, the rate and intensity of depression remained relatively high among the participants who did not do MBCT.

Anxiety levels diminished – Anxiety levels fell significantly among participants who did MBCT but not among people in the control group. By week 20, symptoms of anxiety continued to be low among participants who did MBCT.

Quality of life improved – Stress levels were generally high among participants at the start of the study. Only in the MBCT group did those levels fall significantly and remain low. The participants from the MBCT group also reported a large and significant improvement in their quality of life, whereas the control group did not report such improvements.

CD4 counts rose – The CD4 counts of participants who received MBCT increased—starting at 555 cells, then rising to 614 cells at week 8 and to 681 cells at week 20. By contrast, the CD4 counts of the control group remained stable.

Most of these findings are in line with those reported from earlier studies. But the change in CD4 counts among MBCT participants, though not statistically significant, was unexpected. It cannot be explained by changes in HIV treatment regimens, as none of the participants changed their meds during the study. There were also no changes in the proportion of participants whose viral load fell below the 20 copies/ml mark. Such changes, had they occurred, could have had an impact on CD4 count.

So, why the increase in CD4 cells? The researchers point to previous studies that found that mindfulness exercises are associated with decreased levels of blood proteins that are linked to inflammation (for more on inflammation, see Ask the Experts on page 26). The Spanish researchers theorize that by improving the emotional health of participants with MBCT, levels of inflammation were likely reduced, which, in turn, could have helped raise CD4 counts. But more research is needed before this theory can be confirmed.

Due to the relatively small size of the Spanish trial and the lack of long-term followup, we cannot say with certainty that mindfulness-based approaches will work for every HIV-positive person who is experiencing depression and anxiety, but a growing body of research suggests that this approach looks extremely promising. +



INVISIBLE

In Search of the

MAN

Straight men and
HIV in Canada

BY SOPHIE WERTHEIMER

When AIDS first became a public health concern in the early 1980s, many people tried to turn away from it and pretend it didn't exist. Since that time, people with HIV have fought relentlessly for visibility, rights and services. But one group of people with HIV has remained largely invisible and has rarely been named in the history of this modern epidemic: straight men.

EPIDEMIOLOGICAL INVISIBILITY

Though the Public Health Agency of Canada's most recent statistics (2013) attributed 19.6% of HIV cases in men to heterosexual contact, straight men seem to have been largely left out of discussions about HIV and the services established to respond to it. Instead, straight men and the programs delivered to them are subsumed under other categories: injection drug users, Aboriginal communities, African Caribbean and black (ACB) men, or men from countries where HIV is endemic. G., a 50-year-old HIV-positive man from Ottawa, says: "It's not that heterosexual men are not at risk, it's that we're not seen as a risk group. We're a subgroup of other groups."

Like everyone, straight men have multiple, overlapping identities, but in the world of HIV some of these identities are given a great deal of attention while others are overlooked.

Since his HIV diagnosis more than 20 years ago, G. has been struggling to shake off a label that doesn't—and never did—apply to who he is. "I'm not considered heterosexual. I'm considered a drug addict," he says, referring to the way that epidemiological statistics reflect how HIV is transmitted. "I don't like having that label put on me because that's not who I am. I may have gotten the virus that way but to have to live with that label for my whole life because of one incident all those years ago is really unfair."

Their epidemiological invisibility may be contributing to the lack of appropriate services for straight men with HIV. Dr. Tony Antoniou, a pharmacist at St. Michael's Hospital in Toronto, is one of the few researchers working with this population in Canada. His research grew out of his clinical work: "We would see these men who became engaged in care very late in their illness and we realized how little support there was for them. Most of these guys were going through this completely alone." Patrick, a man in his late forties who lives in Toronto and was diagnosed with HIV in 2009, agrees: "There's no real sense of community among straight men with HIV."

Over the last few years, Antoniou has organized focus groups and community events with HIV-positive straight men across Ontario to identify priorities. A key priority is

to have straight men recognized as a group in its own right. “The thing that these men want to achieve more than anything is to have their sexual identity recognized,” Antoniou says.

INVISIBILITY PREVENTS DIAGNOSIS

Invisibility not only has the effect of isolating straight men living with HIV but also limits the possibility that a straight man will be diagnosed in the first place. Greg Riehl, a registered nurse who works with indigenous communities in Regina, notes that while HIV testing should be routinely offered, many of those performing the tests assume that “if you’re a heterosexual man, you’re doing things properly [in terms of HIV prevention] or you’re not one of the target or at-risk populations.” As a result, testing isn’t offered to these men.

Fanta Ongoiba, executive director of Africans in Partnership Against AIDS (APAA), and Winston Husbands, director of research at the AIDS Committee of Toronto (ACT), also find that black men are being tested for HIV and diagnosed less routinely than black women: “We know that in terms of heterosexual transmission, there are more black men living with HIV than black women,” says Husbands. “But black men are not being tested and diagnosed for HIV to the same degree as black women, so that’s a real problem.”

THE BURDEN OF HIV CRIMINALIZATION

While straight men tend to be invisible in much of the story of HIV in Canada, one area where they clearly appear is in the sphere of the criminalization of HIV non-disclosure. This point comes up frequently among the straight men participating in Antoniou’s research. He and the men he works with have observed that portraits of straight men with HIV in the media are often monstrous: “They are depicted as being threats to their community, as being these shady people who are deliberately infecting women.”

G. takes Antoniou’s argument a step further. “Heterosexual men are under a lot of stress in terms of what it means to be male and heterosexual,” he says. “We are looked on as predators and potential rapists and criminals. And at the same time we’re not trained to discuss our feelings or to explore other aspects of our personalities, our humanness, because of a fear that it may be compromising to our masculinity.”

Black men may constitute the majority of those who have been accused and tried in Canada, and they have been particularly vilified by the media. ACT’s Winston Husbands says that the idea perpetuated by media accounts “that black men are difficult to work with in terms of service provision, that they are out of control, gets in the way of understanding black men’s experiences.”

“If I find an HIV-negative woman, how do I tell her about my HIV without losing her?”

MASCULINE IDENTITY

For many men, being a wage earner is a source of pride rooted in their sense of masculine identity. But living with HIV often means living with reduced financial means and, in some cases, becoming dependent on monthly government disability cheques.

Luc-Edgard Douyon, coordinator of *Projet Info-Hommes* (the Men’s Information Project) at GAP-VIES, a Montreal HIV organization working primarily with Haitian and immigrant communities, emphasizes the importance of the masculine role of breadwinner to the straight men that he works with: “If a man cannot take care of his financial commitments, then there is something missing. A ‘real’ man must be independent and face his commitments, both on the family and financial front.”

DATING AND RELATIONSHIPS

Relationships with women emerge as a key priority in the research that Antoniou has been undertaking with HIV-positive straight men. He notes that “there’s a big focus on developing meaningful relationships with women, but there’s also this fear that if I find an HIV-negative woman, how do I tell her about my HIV without losing her?”

Two days after being diagnosed with HIV, Patrick attended a social event in Toronto for straight people living with HIV. Though he was terrified at first, this experience helped to normalize HIV in his mind and he realized that living with HIV didn’t mean “glowing in the dark or having two heads.” A year later, he took over the responsibility of organizing these events with the aim of continuing to offer straight men and women living with HIV the opportunity to meet in a casual atmosphere.

The limited finances that many people with HIV have to contend with can restrict their opportunities for socializing and developing meaningful relationships. Patrick noticed this pattern when attendance at the social events he was organizing in restaurants started to drop off. “What I came to realize was that about half of the men and women didn’t have a lot of money. I kept hearing that some just couldn’t afford to come.” Despite these barriers, he knows of at least one successful meeting to have come out of these events: “At one of the parties I held, I met a girl. To this day she’s my girlfriend and we have a son together.”

Disclosure and confidentiality remain important concerns for straight men with HIV even once they are in relationships and have families. Antoniou notes that the fathers he has been working with “worry about the stigma [of HIV] being transferred to their children.” In fact, his newest research project is examining issues related to

fatherhood for men who are living with HIV, an area that has seldom been addressed in Canada or internationally.

CREATING SERVICES

Straight men with HIV may need help and support, but it is difficult to find. As GAP-VIES' Douyon notes, "Every program is designed either for gay men or women. Heterosexual men are really left behind in terms of interventions offered to them."

G. agrees: "In all this time, I've never had any outside help and it's only by sheer force of will, and with the help of my wife, that I have managed not only to stay healthy but to keep on with the sometimes arduous medical regimens that people with HIV have to undergo."

When asked what services would look like for straight men who are living with HIV, G. is momentarily at a loss: "I wouldn't even know where to begin. I've made do with so little over the years." But on further reflection, he identifies a number of services he would find useful, including employment services, social gatherings and exchanging HIV treatment information with peers.

Recognizing the importance of straight men with HIV connecting with one another, a growing number of organizations have recently started to offer activities to this underserved population. This has included the creation of support groups, opportunities to socialize, as well as activities like APAA's annual summer BBQ for straight men, their partners and families.

Patrick says that a casual approach is key to providing services to straight men. "Men are generally more like lone wolves than women. When they've got a problem, they're more inclined to hide away than go out and talk about it. So I think this is a really good way, having social events where you're going to have fun. As a side benefit, you get to talk to people who understand you, make some friends and become less isolated."

Researcher Antoniou urges service providers to think about how straight men relate to one another. "The best ways to reach these guys may not be through meetings at agencies. Non-traditional venues or activities like a bowling night may be more effective."

Recognizing that services may be more successful if they meet men "where they're at" has also led to the development of innovative HIV

prevention programs. For example, GAP-VIES does outreach in barbershops and parking garages and with airport taxi drivers in Montreal. Douyon explains: "They play dominoes or cards while waiting for the planes to arrive and for new clients to come in, so we use that opportunity to talk to them and to conduct prevention activities. We distribute condoms, brochures, promote testing and we also demonstrate how to put on a condom."

HIV nurse Greg Riehl notes that working with soon-to-be fathers offers another interesting opportunity for reaching out to positive straight men. "As we're identifying women with HIV through prenatal testing, what better time to engage expectant fathers and bring them into care? They can be role models for their sons further down the line."

ENGAGING MALE VULNERABILITY

Slowly but surely, straight men are carving out a space for themselves in the story of HIV in Canada, one that goes beyond the limited stereotypes and narratives of what it means to be a man in our society. Antoniou observes that "for some men, it has been trying to get on the boards of

ASOs, volunteering, trying to get some visibility...trying to get the attention of people in their communities who might be able to help them." G. believes that learning from other communities may also be helpful. "Women with HIV were really good at getting organized, and maybe they could mentor us, which would be great."

Winston Husbands and Fanta Ongoiba both insist that "instead of taking the idea that 'straight men do not want to engage' for granted, we have to find out what that is all about. There is some truth to it, of course, but what kind of expectations are men putting on themselves and what kind of expectations are societies putting on them?" Through their work, Husbands explains, they have tried to demystify the stereotypes "that black men are hard, they can't show emotion, they're ruthless and reckless." Husbands has found that, as a result, men are acknowledging and engaging their vulnerability.

G. agrees that engaging straight men's vulnerability is key. "Men are always told to not express their feelings but this is precisely what we need to do. If men want to grow as human beings, we need to understand that our roles need to be expanded. And that comes with learning to ask for help." +

RESOURCES FOR STRAIGHT MEN

These organizations offer support groups and/or activities for straight men:

- **AIDS Committee of Ottawa** (aco-cso.ca)
- **GAP-VIES** (gapvies.ca) and **Maison Plein Coeur in Montreal** (maisonpleincoeur.org)
- **The AIDS Committee of Cambridge, Kitchener, Waterloo & Area** (acckwa.com)
- **Africans in Partnership Against AIDS** in Toronto (apaa.ca)
- The Dudes Club, a men's support and education group at the **Vancouver Native Health Society**, open to men of all sexual orientations (dudesclub.ca)
- **Pozsocial.ca**, an online resource for straight men and women living with HIV in Canada (If you are planning an activity to reach straight people with HIV and need help promoting it, contact Colin at colin@possocial.ca)



Adherence All-Stars

Diane Peters meets a group of PHAs with “chaotic lifestyles” and finds out how, despite major obstacles, they adhere to their meds.

ILLUSTRATION BY GREG STEVENSON

“My doctor says I’m her star patient,” Dwight Barker brags. He’s got a right to: He takes his HIV meds like clockwork and his viral load has been undetectable for almost three years. “No matter what, I take my pills every day. It helps that as soon as I open my eyes I can see the pill bottles on my night table and I take them before I get out of bed.”

Reaching star status has not been easy for Barker, who’s 46. He was diagnosed with HIV in 2010, but suspects he contracted the virus the previous summer when he was living in Vancouver and injecting drugs.

Barker eventually moved to the Edmonton area to get away from the Vancouver drug scene but he started using again. During a five-month relapse, he was unable to take his HIV meds for 12 days straight because someone stole his pills and he couldn’t get to a doctor for a new prescription. But he was lucky: His high CD4 count and low viral load remained unchanged.

Before starting on HIV meds Barker’s health was in decline, so he knows how bad things could get without them. He’s seen friends get sick quickly after tossing their medications aside. And he’s extra-motivated when he’s dating someone—he does not want to pass the virus on to a sex partner and knows that when his viral load is low, his HIV transmission risk stays low, too.

Drug-free since 2014, Barker now has a part-time job and does peer support for HIV Edmonton. He still has his

struggles with anxiety and with fractured relationships in his family, but his ability to stick to his meds through chaotic times is helping experts understand how people can stay adherent even when the odds are stacked against them.

★ *What’s your secret?*

University of Alberta School of Public Health instructor Megan Lefebvre conducted a unique study with the Northern Alberta HIV Program (NAHIV) to find out just why Barker and 12 others with self-described “chaotic lives” adhere so well to their meds.

The participants have indeed struggled with obstacles: homelessness, drug addictions, mental health issues, abuse, jail and co-infections. But NAHIV clinic staff had noticed that these clients were superstars when it came to adherence. Lefebvre decided to find out more. “The research always asks, what are the barriers?” she says. “We wanted to ask them: What’s your secret to success? How can you do this? We wanted to learn from them.”

Lefebvre’s community-based, participatory research project involved in-depth discussions with the 13 members of this group, who, along with clinic staff, helped develop the interview questions.

Working around the central question, “What is your secret for taking your HIV medication all the time?” Lefebvre learned about people’s motivations and strategies

for staying adherent. Common explanations included not wanting to die from HIV, family ties, wanting to protect others from the virus and having something to look forward to in the future. “I don’t want to hurt the people that love me,” confided one participant, while another stated simply, “I’m moving into a new apartment next month.” Through these interviews, Lefebvre discovered that what’s considered a chore for many people with HIV is actually an opportunity for success and celebration for others.

It all boils down to a sense of control, according to Lefebvre. “These people felt they had little or no control over their daily lives. But by taking their HIV meds regularly, they could have control over something.” Experiencing that sense of being in charge, in turn helped them make other positive life choices, such as renewing relationships with estranged family members or volunteering.

As a result of Lefebvre’s research, clinical practices at NAHIV have changed. Lefebvre recounts how one of the clinic’s nurses had remarked, “I didn’t know about my client’s families. I didn’t ask about that. I believed I didn’t have time.” But, once staff understood the importance of family in motivating patients to stay adherent, they began to ask regularly about people’s partners, kids, parents and siblings. If patients didn’t have families, the clinic staff tried to act more like “family” to them, learning about patients’ lives and goals, and keeping this conversation active from one visit to another. As a result, many in this group of adherence VIPs felt closely connected to their healthcare team and relished the support they got for their great adherence record. “Society often tells them negative things about themselves,” Lefebvre says “but this is something they can do and get recognized for.”

Simpler HIV drug regimens

Treatment for HIV gets better all the time. Today’s medications are easier to take, cause fewer side effects and many formulations require just one dose a day. But there’s still a big catch: Adherence has to be high or the virus can start reproducing, leading to drug resistance, fewer treatment options and, eventually, illness. Studies from the past decade or so have indicated that an adherence rate of about 95 percent is ideal for achieving the best health outcomes. “That means if you take 30 pills a month, you can only miss two, not even,” says Linda Robinson, an HIV clinical pharmacist in Windsor, Ontario.

Some of today’s meds are longer acting, so if you miss a dose, there may still be enough drug in the body to keep the virus under control. “But it’s a fine line,” Robinson says—and experts don’t know the precise point at which the drugs will stop working for an individual. People with existing drug resistance, co-infections or other underlying health conditions not related to HIV likely need to be more careful.

The bottom line is that getting into the routine of taking pills every single day exactly as prescribed and directed is still key and missing pills here and there can lead to drug resistance, health problems and the risk of HIV transmission.

Barriers to adherence

Taking a pill once or twice a day may sound simple, but over a lifetime of pill-taking, it is a challenge, especially for those who face additional obstacles.

Research in the past decade has established that certain factors impact adherence rates. Between 2007 and 2010, British Columbia’s LISA (Longitudinal Investigation into Supportive and Ancillary Health Services) cohort enrolled 566 participants with HIV who were taking antiretroviral therapy. Their research found that only 316 participants (55.8%) were “optimally adherent,” or took their meds at least 95% of the time. In particular, they noted that women and people using injection drugs struggled most with adherence.

Depression and other mental health challenges can put people at risk for poor adherence. The BC study found that this was particularly so among women. Not surprisingly, going to jail can disrupt a medication schedule, as can moving from one province to another (and therefore one provincial medication coverage plan to another) or periods of homelessness. “Where are you going to keep your meds?” asks Dr. Stan Houston, professor of medicine and public health at the University of Alberta and director of NAHIV. “Someone can steal your backpack at the shelter. But also, all your energy is devoted to what you are going to eat and where you are going to stay tonight. Taking pills may drop down on the priority list.”

Immigrants and refugees in Canada who are living with HIV face considerable hurdles, including access to medications and privacy concerns that impact their ability to store and take meds. And, of course, HIV meds can cause unpleasant side effects—gas, fatigue or sleep problems—which can be real de-motivators to popping those pills.

New approaches to adherence

To address these issues, healthcare providers can offer extra help to reduce the barriers to taking medications. This may mean changing meds to avoid certain side effects, or creating a more convenient medication schedule. Dosesets and blister packs available through the pharmacy can help organize a complex medication schedule, as can assistive adherence apps.

But many HIV healthcare providers are beginning to look more closely at adherence as an acquired habit or behaviour. “People’s circumstances dictate their ability to adhere,” says pharmacist Linda Robinson. “That, combined with their own personality or behaviour patterns. Adherence is a behaviour.”

Some people are creatures of habit and have a set routine, no matter what’s going on in their lives. Others change what they do and how they do it daily. Most people have points in their days that are more predictable than others. So the most successful approaches to adherence take into account the whole person with a very individualized adherence approach (see opposite page). “It’s a question



Adherence tips

- Take your medication at the same time(s) each day.
- Use the alarm on your cell phone, a pager or other reminder device.
- Use a pill box to take extra doses of medications with you when you are out.
- Get your pharmacy to put your medications in a weekly dosette or blister pack.
- Keep backup supplies of your meds at places where you regularly stay (like your workplace or partner's home).
- Plan ahead for weekends, holidays and travel.
- Make sure you don't run out of your medications.
- Talk to other people with HIV and learn from their experiences.
- Develop a supportive network of people who can help remind you to take your medications.

of figuring out a way of integrating a habit into your life," explains NAHIV's Dr. Stan Houston.

TACKLING SIDE EFFECTS

An individualized approach to adherence often starts with tackling side effects. Dr. Houston always questions his patients closely about side effects and how they are impacting their lives. "Ask. Never assume," he cautions. Some people don't mind digestive concerns while others, perhaps because of their work or living situation, really struggle to keep taking meds that cause these side effects. Again, these issues are so individual that doctors need to listen closely as their patients explain how certain aspects of their meds affect them and let that determine the next move.

ESTABLISHING MOTIVATION

Next, it's about establishing motivation. To help people grasp how their meds work and the benefits of sticking to their regimen, Robinson uses props like a balance scale to show how HIV drugs hold the viral load down and allow CD4 counts to rise.

Effective healthcare providers make sure their message is about teamwork and support, not judgment. "You have to be non-judgmental with your patients," Houston says. "You have to convey the idea that we both know adherence is important and it's part of both of our jobs to support it."

PLAYING PIGGYBACK

Then, it's on to finding a trick or technique that works. Some clinics send emails or text reminders to help patients adhere. But perhaps the ideal is to identify a daily routine on which to piggyback pill taking. One of Dr. Houston's

patients with great adherence picks up his HIV meds every morning from the pharmacy on his daily trip to the liquor store.



Slip, fall and get back on your feet

The best-laid plans can fail, and those taking meds for many years are at risk for slipping—particularly when life changes.

That's what happened to Alexandra de Kiewit. She took her HIV meds regularly for six years. Then, last fall, she started treatment for hepatitis C. A former injection drug user, de Kiewit was also working nights at a Montreal needle exchange. "The morning pill for HIV became so hard for me to take," she says. "Sometimes in the morning, I'd be fast asleep." Taking her evening pill, which she always did with dinner, stayed firmly entrenched in her routine.

Finally, six months later, she realized her medication schedule was not working and never would. A visit to her doctor resulted in a new regimen with a single HIV pill she could take at dinner.

Now, de Kiewit has been able to adhere well again, and is extremely motivated to keep it up, as she and her HIV-negative partner are trying to get pregnant. After discussions with the doctor, they both understand that de Kiewit's viral load has to be undetectable in order to have the best chance of conceiving naturally without her partner becoming positive. "At first I took my medication for me, because I don't want to get sick," says de Kiewit, "but now I take it because of my relationship as well."



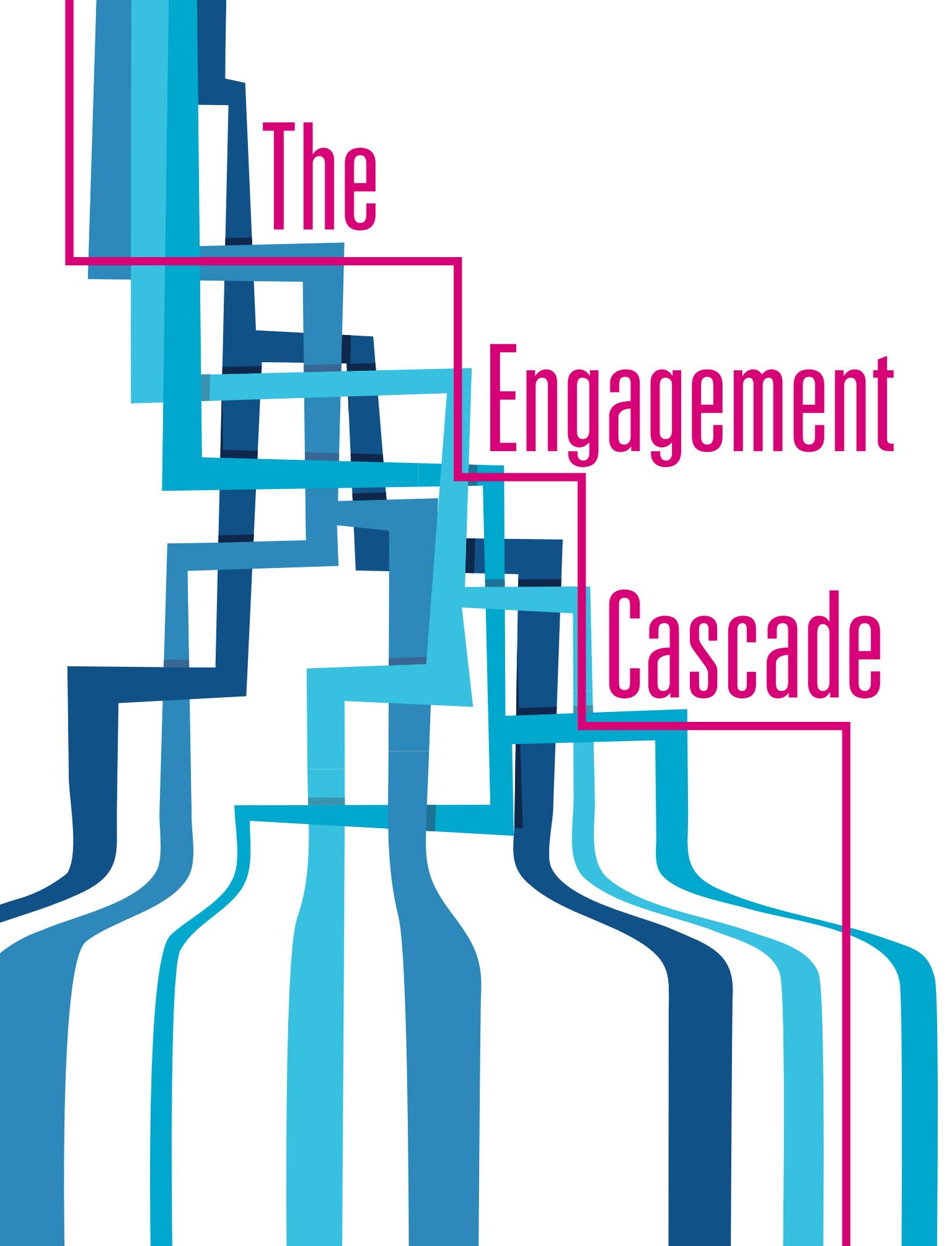
Research that keeps on giving

Back in Edmonton, Megan Lefebvre's research became more than just a PhD thesis. She and six study participants decided to take what they discovered about superstar adherence and share it with others—healthcare workers, researchers and people who are HIV positive and struggling with medication adherence.

They made a video called *Living with HIV and it's OK* and screened it at HIV Edmonton at a series of pizza parties. Study participants acted as peer educators and HIV Edmonton clients enjoyed learning from "the celebrities" themselves. "It really humanized the issue of adherence," Lefebvre says. The pizza nights became so successful that the study participants continued to show this video and animate conversations about the importance of adherence throughout their communities. +

Diane Peters is a Toronto-based freelance writer, editor and teacher. She writes about health, business, parenting and other issues.

To see Megan Lefebvre explain her research at the Northern Alberta HIV Program, check out "Adherence Among Chaos" at [youtube.com/watch?v=P9VY13DOvI8](https://www.youtube.com/watch?v=P9VY13DOvI8)



The

Engagement

Cascade

David Hoe
reports on
the latest
tool for
helping
people with
HIV to
reconnect
with their
health.

What to do when someone gets stuck and becomes used to neglecting their HIV care? Perhaps doesn't even think of him or herself as "neglecting" their care? I should ask myself, really.

Recently, I decided to ask my doctor about my intestinal troubles—bloating and discomfort. "Oh," he said about the bloating, "that would be the meds you're on. Let's change them. There are lots to choose from now." I had been putting up with this for 10 years! Granted, I was satisfied with having an undetectable viral load and a fairly good CD4 count, and I generally felt well. But why did I wait all this time to ask?

"Ah," the doctor continued, "I see you have some abnormal cells in your rectum. I'd missed that." Once we got into a groove, I started asking about other things: "What about experimenting with stopping my antidepressants? What about...what about...?" And so it went.

It took a bit of time for me to bring up all the issues that were concerning me rather than the settling-for-what-is I had gotten used to. I realized that I had progressively reduced my HIV care and that I had not been to see my doctor for nearly a year.

Living well with HIV is a lifelong commitment that requires paying attention to our whole selves—our body as well as our mind and soul—and to many aspects of our lives. This includes making regular use of services—medical as well as other health and wellness programs—to improve our well-being. If we are not attentive to our own care, we do not do so well. These days, more and more of us are able to enjoy a longer life because of effective HIV medications and, perhaps more importantly, because we are paying better attention to ourselves.

We know that medical care is essential, but how can we engage meaningfully to improve our overall well-being and quality of life? What do we, as people living with HIV (PHAs), need to be aware of that affects how well we are, and how well we can become?

A group of PHAs asked ourselves these questions. The Poz Prevention Working Group of the Ontario Gay Men's Sexual Health Alliance is made up of gay men from Ontario but the issues we discuss are, we believe, relevant to all people living with HIV.

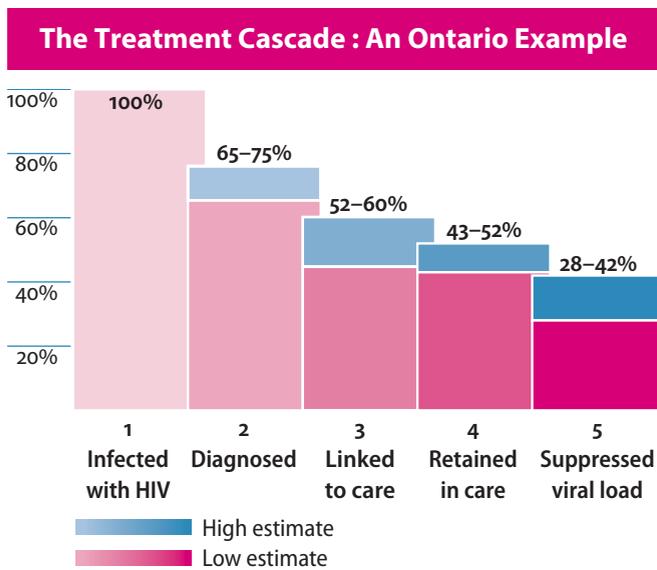
We produced a discussion paper that looks at the engagement of people with HIV in treatment, prevention, care and life enhancement. In response to the HIV treatment cascade—a model that shows how well people with HIV are connected to the continuum of treatment-related services—we developed a model that we named the engagement cascade. Our goal was to reframe the treatment cascade to be more holistic and to better reflect the realities and lives of people living with HIV in order to help people take charge of their own engagement and care. We also wanted to educate those who provide care and services to us.

THE TREATMENT CASCADE

Think of a waterfall cascading downward over rocks and ledges, losing speed and intensity as it meets these barriers,

and finally emptying into a pool below. The treatment cascade uses the image of a waterfall to show the diminishing engagement of people with HIV in HIV-related services, from testing to care and, ultimately, effective treatment with its proven prevention benefits.

Of the estimated total number of people living with HIV (1), the treatment cascade shows the percentage of us who have been diagnosed (2). Of those diagnosed, it shows a still smaller percentage who have been linked to health care (3). Of those initially linked to care, it shows the still smaller number of people who stay in contact with their care providers over time (4). Finally, the smallest number of all is those who have a suppressed viral load (5).



Note: Data reported as current estimate, but some data comes from Remis (2009, 2011, 2012), PHO Lab (2007–2008) and OCS (2011).

The treatment cascade raises the question: How does the health of so many people with HIV manage to dribble away through the cracks of health care, social services and treatment? How can we plug these leaks?

HIV epidemiologists are placing a great deal of emphasis on the collection of accurate information to inform the development of treatment cascades in locations across Canada. Right now, many jurisdictions are working to develop one. While Canada doesn't have a national treatment cascade, British Columbia and Ontario have cascades that reflect provincial data. Researchers in Alberta also created a cascade based on data collected at the Southern Alberta HIV Clinic in Calgary. These numbers help to identify specific weaknesses and gaps in services, with the goal of helping as many people as possible to achieve and maintain viral suppression. This is good both for the health of people living with HIV and for preventing transmission of the virus.

The treatment cascade captures how well the healthcare system helps us to engage and stay engaged in the continuum of services and to what extent it falls short. It provides us a

picture of the gaps in HIV-related services, raising important questions about how we can close those gaps:

- How can testing be made more widely available so that the nearly one in four people living with HIV who are unaware of their HIV status can take steps to protect their health and the health of others?
- How can service providers and policymakers ensure that all people living with HIV are linked to and retained in care?
- How can HIV treatment be made more widely available?
- How can people be supported to take their meds so they can achieve an undetectable viral load?
- How can we best ensure that the enormous benefits of HIV treatment are realized?

In this way, the treatment cascade offers us a valuable tool.

What the epidemiological information of the treatment cascade does not capture are the lives and experiences of people living with HIV. It does not tell us about stigma and discrimination and what happens in our lives that influences our engagement in healthcare and our attention to our well-being. When a barrier prevents us from getting the care we need, it shows up in the cascade, but we don't see the story behind it. Consider, for example, a young woman who leaves an abusive partner and moves to another town. She forgets her meds when she moves to safety. Amid the chaos she gets used to not taking her meds and does not connect with a new doctor. In the treatment cascade, it would merely register that this woman had not been retained in care.

THE ENGAGEMENT CASCADE

The engagement cascade takes another approach—one that starts from the perspective of people living with HIV. When the Poz Prevention Working Group of the Ontario Gay Men's Sexual Health Alliance set out to reframe the HIV treatment cascade to take into account our lived realities, we asked: What do we need to be meaningfully engaged in every aspect of our treatment and care? This is first and foremost about honouring the needs and lives of all PHAS, acknowledging that the great majority of people with HIV try to do the best with what they have, and about improving our experiences of living with HIV. This will impact our health outcomes and help close the gaps we see in the treatment cascade.

Every day we make dozens of decisions that have an impact on our quality of life—what we eat, how we play, what we think about ourselves as we wake up, how we manage our addictions, how our love life is going, how we see our bodies, and so on.

In the middle of all of these decisions is HIV. Most of us would probably say that the arrival of an HIV-positive test result makes us rethink life. From then on, it becomes a player in our lives—sometimes more, sometimes less.

Engagement is more than just showing up for your doctors appointments; it's a holistic attitude toward your role in your health. The healthier we are as individuals—physically,

mentally, spiritually, emotionally—the more we are able to have meaningful relationships with the people we care about and the communities we’re a part of. For some people with HIV—those of us who were raised to value and care for our bodies and minds, those of us who have a spiritual practice, a *raison d’être* or a loving connection to our community—becoming and staying healthy may be relatively easy, requiring a few tune-ups and tweaks now and then. But many of us struggle for much of our life to be fully healthy and need a great deal of support along the way.

In developing the engagement cascade, we attempted to capture what we need to pay attention to about ourselves and how healthcare and other service providers can support our engagement and deliver PHA-centred care.

We’ve pinpointed six main considerations and created a handy tool to help PHAs and healthcare providers use these six statements. At any time of doubt, feeling disconnected or wondering about next steps, PHAs and healthcare

providers can use this tool to reflect or prompt a helpful discussion.

Gone are the days of expecting a shorter life, when our sole concern was survival. If you have not seen your doctor for a while or there’s a part of you that feels stuck and that is influencing your care and engagement, reflect on these six points.

In truth, it was in writing this article that I asked myself: “Well, what about me? Am I getting what I want as I get older? Can I feel more vibrant and well in any way?” Since I have begun to put myself first again, my sleep is better and my stomach is happier. I plan to keep checking in with myself periodically to see what else I can do to get more energy and balance in life. +

David Hoe is a life coach who has been living with HIV since 1984. Don’t miss his interview in “Sexual Healing” in the Fall/Winter 2015 issue of *The Positive Side*.

For people living with HIV

I matter. Every person matters. You matter and are an important part of humanity.

What you think, feel and do will make a difference to what happens next! If you don’t think you are important and precious, then it is more likely that you will ignore your care. Taking care means seeing ourselves as important and worthy of attention.

I belong. What can you do to feel more connected to others? Creating a sense of belonging and safety will help foster your health and wellness. Belonging is about a sense of social inclusion and knowing who the best people are to have around you.

I participate. What are you doing to play an active role in your healthcare and overall wellness?

Ask all the questions you have about your health and wellness. You have a right to ask questions and make informed choices.

I access. Are you getting the services you want and need? Take the time to think about your health and how it can be improved. What can you do to help make it happen? Are there resources and supports that could help you with your mental health, stress, sleep, addictions, sexual health and HIV care?

I contribute. What can you do for yourself and for others? How can you give to yourself and others in ways that will make a difference? Take the time to imagine better things for yourself and others—and act on those ideas.

I desire. What in life do you want more of? You were born with passion and the right to live as you choose. HIV doesn’t change that. Pursuing your wishes and dreams will make a big difference to your overall health and well-being. Experiment and see what excites you.

For service providers

My client matters. Value each of us as human beings and recognize that we are the experts of our own experience. Ask us questions and give us opportunities to participate fully in our care.

While symptoms and test results may be what get recorded in our charts, those are but one small sliver of what matters to our health and the interaction we have with you.

My client belongs. Take a look at how we are connected to the people around us and explore how we might make our homes, workplaces and communities safer and more welcoming.

My client participates. Make sure you leave space and opportunity for us to ask questions and give opinions.

My client accesses. Are you aware of the services—healthcare, social services, financial supports—that could benefit our health and wellness? What can you do to help us connect with services? What doors can you open?

My client has opportunities to contribute. How you can support and encourage our self-care and opportunities for us to care for others?

My client desires. Make time to ask us about our goals and wishes for the future. And take time to listen.



Inflammation

Some experts call it inflammation, others call it immune activation. What they all agree on is that it's chronic and it must be reduced. Three healthcare providers sound off on the mounting evidence of interactions between inflammation and HIV.

INTERVIEWS BY RONNILYN PUSTIL

PAUL MACPHERSON

Specialist in Infectious Diseases
The Ottawa Hospital

With effective antiretroviral therapy (ART), many people with HIV can now anticipate a near-normal lifespan. Looking back over the past 20 years, where we are today can only be considered a triumph of modern medicine. However, as people with HIV live longer, new challenges in treatment and care are coming to light. Chronic inflammation is likely central to many of these challenges.

Whether this is inflammation in the classic sense (think of the redness and swelling associated with an infected cut) or better described as chronic (long-term) activation of the

immune system is a matter of debate among immunologists. Regardless, it is clear that even with effective ART the immune systems of people with HIV show signs of persistent activation.

What drives this immune activation remains unclear. One possibility

is ongoing, low-level HIV replication in various places in the body that ART drugs cannot reach. Different parts of the body can have different levels of HIV suppression based on the virus' ability to replicate, how well drugs can get to that part of the body and

INFLAMMATION 101

Inflammation is part of your body's response to injury or infection. Under the right circumstances it is beneficial to the body, as we could not heal without it. There are two types of inflammation: acute, which tends to be time-limited, and chronic, which is more of an ongoing process. Chronic inflammation causes damage to tissue, as well as ongoing pain, scarring and an accumulation of white blood cells. Fighting a long-term chronic infection like HIV throws the immune system into an ongoing state of activation, or chronic inflammation.

the body's ability to fight HIV there. There is now clear evidence that an undetectable viral load in the blood does not ensure that HIV is not replicating to some degree in other tissues.

While persistent low-level HIV replication could drive ongoing immune activation, it is also possible that this immune activation drives HIV replication, setting up a vicious cycle. Another potential explanation for chronic inflammation in people with HIV is the fact that bacteria and associated proteins can "leak" into the blood from the gut and activate the immune system. Other explanations include co-infection with CMV (cytomegalovirus) and problems in the regulation of some cytokines, chemical messengers in the body.

Regardless of the underlying cause or causes, the *effects* of chronic immune activation are only now starting to be recognized. Evidence suggests a strong link between chronic inflammation and the development of heart disease. Other possible outcomes may include brain and cognition problems, premature aging and even kidney dysfunction.

Much research still needs to be done to better understand the long-term effects of chronic inflammation, what is driving it and how to reverse it. If the past 20 years are any indication, these challenges will not be insurmountable.

MARIANNE HARRIS

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Any type of chronic infection, such as HIV or hepatitis B or C, will activate the immune system and cause chronic inflammation. Over the long term, inflammation damages the blood vessels and organs, increasing your risk of conditions like heart, kidney and lung disease.

Treating HIV infection with antiretroviral therapy greatly reduces inflammation but does not get rid of it completely, so people living with HIV are at increased risk of these other conditions.

If you have HIV, the best way to reduce inflammation and decrease your risk of these conditions is to **take antiretroviral therapy** consistently and continuously. You should also receive treatment for hepatitis B or C, or any other chronic infections you may have.

Another important way to reduce inflammation is to **quit smoking**. Smoking tobacco increases inflammation throughout the body, increasing your risk of heart, kidney and lung disease as well as osteoporosis (weakened bones) and many cancers.

What else can you do to reduce inflammation? Obesity and stress can increase inflammation, so it's important to **maintain an ideal weight by eating a healthy diet and getting regular exercise**. **Coping with stress and getting enough sleep** are likewise important for reducing inflammation and maintaining overall good health.

Should you be taking antioxidant supplements or enriching your diet with foods that are high in antioxidants? My advice to patients is no. With the exception of vitamin D, there is no evidence that taking antioxidants will decrease your levels of HIV-related inflammation, improve your health or increase your lifespan. In fact, high levels of some antioxidants (beta carotene, vitamin E and possibly vitamin A) may be associated with an increased risk of death.

There is some evidence that adequate levels of **vitamin D** are associated with a lower likelihood of several inflammatory conditions, including heart disease, diabetes, bone disease and certain cancers. The ideal amount of vitamin D for people with HIV is unknown, but a daily intake of 1,000 to 2,000 international units (IU) of vitamin D₃ is probably enough and certainly safe. Vitamin D supplements are inexpensive and can safely be taken with antiretroviral drugs.

TASLEEM KASSAM

Naturopathic Doctor
Effective Health Solutions
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Several studies suggest that chronic HIV infection creates a state of

premature aging and inflammation that can lead to other chronic diseases. Here is the advice I give to my patients for reducing inflammation:

Eat well. Aim for a diet rich in colourful vegetables and lean protein, with moderate amounts of grains, legumes, nuts, seeds and fruit. Protein, the building block of antibodies, is important for a healthy immune system. Supplement with protein powders if needed. Avoid trans fats, refined carbohydrates and processed foods as much as possible.

Manage stress. Stress and inflammation both play a role in cardiovascular disease. To keep your stress to a minimum, do deep-breathing exercises, yoga or Tai Chi and journal regularly.

Exercise. While exercise is good, extreme workouts can cause muscle damage and actually increase inflammation. Moderation is the key.

Mix up the antioxidants. Any antioxidant is going to help repair the damage caused by free radicals, molecules that are produced within cells. I suggest that people get a mix of fat- and water-soluble antioxidants, such as curcumin, astaxanthin with mixed carotenoids, and vitamins C and E (mixed tocopherols).

Take probiotics. The right mix of friendly bacteria in your gut helps to keep your digestive tract healthy and benefits many other organ systems too.

Sleep. Most of us are sleep deprived without realizing it. To prevent a surge of inflammatory hormones, make healthy and regular sleep habits a priority. Aim for a minimum of eight hours nightly. +

Both the cause of HIV-related inflammation and the best way to treat it remain uncertain. A Canadian study, called the MAINTAIN study, is expected to reveal more about the role that antioxidants and other supplements play in helping the immune system of people living with HIV. To learn more about this study, go to www.hivnet.ubc.ca.



PHOTOGRAPH: TANYA ANDERSON

Space Dates, 2012

A Stitch in Time

**Art + activism + community building
= the social art practice of Jessica Whitbread.**

BY THEODORE KERR

Jessica Whitbread bought herself a blank book in the months following her HIV diagnosis. In it, she pasted images and quotes from magazines, wrote out song lyrics and drew young women with the phrases “When I grow up I want to be a grandma” or “Definition of Life: Terminal Illness” in thought bubbles.

“If I think about it now, this was the way I was dealing with my HIV,” says Whitbread, now 35, “and those girls with the thought bubbles were saying the things my friends could not say to me.”

Living with HIV can be isolating, for women especially so. One in four people living with HIV in Canada is a woman, but as a result of sexism, stigma, discrimination and violence, many HIV-positive women feel silenced. The mainstream media doesn’t often report about women living with HIV and when they do, they tend to perpetuate stereotypes about “innocent victims” or “whores.” HIV community groups aim to be welcoming, but with their emphasis often on gay men’s sexuality these spaces can feel alienating for a lot of women. So

the choice for many women is either to stay quiet about their status or to make their own community—which is exactly what Whitbread did.

Whitbread was diagnosed when she was 21, in January 2002, during a period some have called the “second silence”—the time between the availability of effective antiretroviral therapy in 1996 and the release of the Swiss Statement in 2008, which shed light on the relationship between antiretroviral therapy and HIV transmission.

For those not directly impacted by HIV, it could have seemed like AIDS was over: There were no more AIDS ACTION NOW! marches, community meetings were less raucous and there was little conversation about politics, love and HIV. When Whitbread did find people who were communicating in engaging ways about their HIV status, they were often older gay men. Though her discussions with these men were powerful, they highlighted for her the extent to which women's voices were absent in these dialogues.

It became clear that if she was going to thrive, she had to do more than draw pictures of her ideal friends. Living in Montreal at the time, Whitbread began hanging out with a group of young queers who cultivated cool outsider statuses. They threw parties, which always included sexy games like Slutty Bingo and Smooch-O-Rama. "I would always work the kissing booths," says Whitbread, who was public about her HIV status. "I liked kissing because it was fun, innocent and felt safer than going home with someone."

These events morphed into No Pants, No Problem, a dance party that started in Montreal and has been held all over the world for more than a decade, in places like Melbourne, Mexico City, New Orleans, New York, Washington and Bangkok. Pantless participants are invited into a safe space to dance, play spin the bottle and join the kissing contest, all under multicoloured bunting and banners hand-sewn by Whitbread with in-your-face messages like *Love Positive Women!* and *HIV is not a crime—AIDS profiteering is!*

It was at these parties that Whitbread first created "her" community, not with other women living with HIV—that would come later with another project—but with other young people who felt out of place in the world. "Living with HIV, or being trans, or questioning your sexuality is awkward enough," she says. "I wanted to make something that was campy and awkward for everyone. My thinking was, 'Let's all be a little weird and have fun in that together.'"

Bold in declaring her HIV status, Whitbread has had more of a struggle accepting the label of artist. In the early years, she didn't really think of what she did as art. "The staff at Visual AIDS were the first to reach out to me as an artist and call what I was doing 'art,'" she says.

[In addition to being the name of the following column.] Visual AIDS is a New York-based contemporary arts organization that houses the largest registry of work created by artists living with HIV. It preserves the legacy of HIV-positive artists who have died and collaborates with artists to remind the world that the AIDS crisis is not over. Having worked with Whitbread on a recent Valentines-themed workshop designed to spread love to women living with HIV around the world, Visual AIDS associate director Esther McGowan sees Whitbread's creative practice as a blend of art, activism and community building: "Jessica's voice and face out in the world helps to remind people about HIV's effect on women, especially young women, and is hugely inspirational to young activists."

The art world has a name for what Whitbread is doing: social practice. *New York Times* arts writer Randy Kennedy explains that social practice "blurs the lines among object making, performance, political activism, community organizing, environmentalism and investigative journalism, creating a deeply participatory art that often flourishes outside the gallery and museum system."

The term "social practice" is clearly illustrated in Whitbread's Tea Time. There is no object created—tea parties cannot be framed and hung on a wall. Instead, a performance, or perhaps a community, is created. Women living with HIV are invited by Whitbread to write letters to each other, sharing their stories. These letters, along with a teacup, are then exchanged at intimate tea parties. What started as an innovative research method to uncover health needs among HIV-positive

women for Whitbread's master's thesis has become an ongoing project. And it has put her in contact with women of all ages around the world who are living with HIV.

Creating with women is key to Whitbread's work. With Morgan M. Page she created a performance documented through a short film and image series called *Space Dates*, in which the two queer women, wearing space suits to protect themselves from infection, go on a series of "cute" dates. The project aims to combat serophobia within the world of dating and hook-up culture. The artists describe it as documenting "the intersection of the criminalization of HIV nondisclosure, the 'safer-sex industrial complex' and queer women's sexualities." Whitbread also collaborated with feminist artist Allyson Mitchell. Together they used needlepoint to make the iconic "Fuck Positive Women" poster to generate public conversation about the invisibility and de-sexualization of women living with HIV.

Whitbread's art is not overly concerned with the end product, but rather with the process of stitching diverse people and their experiences together for greater shared understanding. Whitbread sees her practice as largely about building trust and, she says, "feeling that, in the end, things will be OK. People will come through in ways we don't always recognize, or someone else will come along and help." She puts people together so they can be there for each other.

As her relationship with HIV evolved, so too has Whitbread's ability to use art to create community and make friends. Whereas before she drew pictures of imaginary friends to feel less alone, Whitbread now often finds herself sewing at the end of the day, and in every stitch feeling more connected with all the amazing women she knows around the world—living with HIV, together. +

Edmonton-born Theodore Kerr is a Brooklyn-based writer and organizer. Former programs manager of Visual AIDS, he is currently doing graduate work at Union Theological Seminary.



More Than Meets the Eye

On the eve of the 10th anniversary of my HIV diagnosis, I have come to realize that in the wonderful world of HIV, society is increasingly divided into two: HIV-negative people and us, the HIV-positive ones! I don't mean to sound "negaphobic"; quite the opposite—I'm a firm believer in embracing our negative brothers and sisters. But sometimes HIV-negative people can lack a sense of humour. Even now, in the 21st century, we still have to sugar-coat HIV when the time comes to disclose our status, and when we're too "positive" about it, some people judge the casual way we discuss it.

When talking with an HIV-negative friend recently, he was surprised to hear me say, "This year, I'm celebrating 10 years of living with HIV!" He said: "I don't get it. It seems to me that there are better things to celebrate. Life, for example?"

I had to stop walking before I could respond. We were on the Magdalen Islands and the vastness of the Atlantic Ocean stretched before us.

"Celebrating HIV doesn't mean celebrating death! You're looking at only the foreground without seeing the full picture. I can't speak for 16 million HIV-positive people, because no two people deal with HIV in the same way,

but I'm proud of the journey the virus has taken me on. I'm proud of no longer being ashamed of HIV. I'm proud of my small triumphs over discrimination, serophobia and all that baggage that comes with being positive. What surrounds HIV is all the people affected by this virus, and I'm proud to be among them. So, you see, I'm celebrating all those small victories."

On the *Butte du Vent*, the sun's rays were beaming down on us. My friend turned to me and exclaimed: "All right then, let's go have a beer and celebrate!" Cheers! +

—André Quenneville, 56,
Montreal

CONTRIBUTE

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

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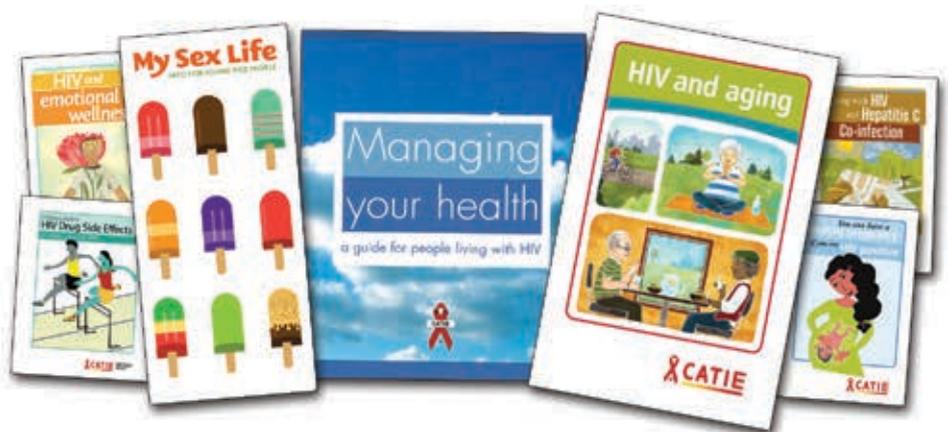
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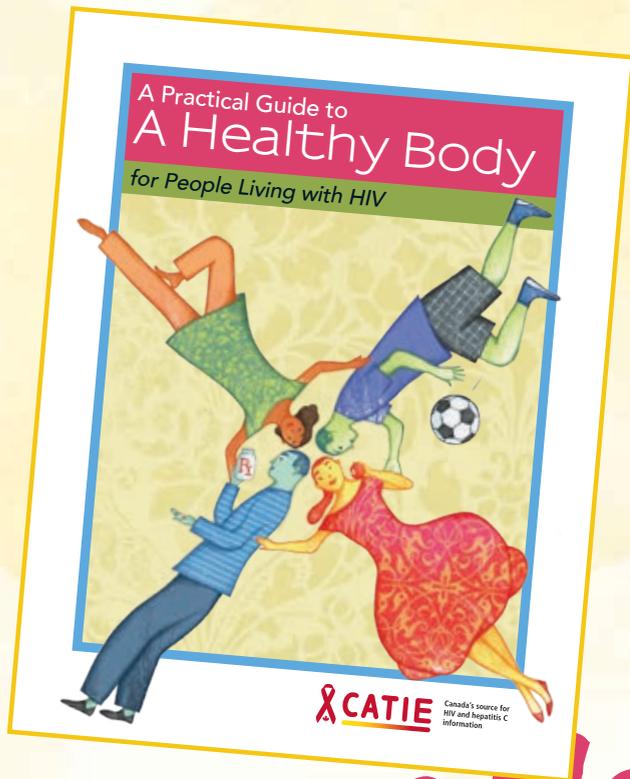
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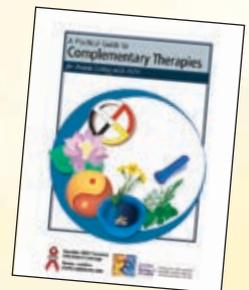
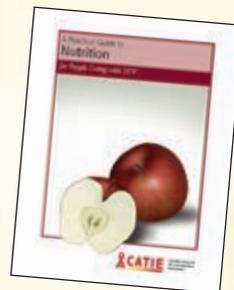
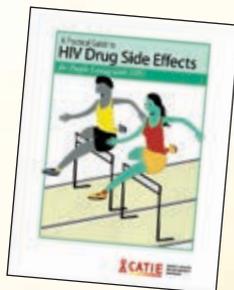
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