

# THE POSITIVE SIDE

## FREEDOM FIGHTER

The impassioned  
activism of  
Gareth Henry

Advice from  
poz women

Western medicine  
meets Indigenous  
healing

The lowdown on  
anal cancer

Artist Gustavo  
Hannecke



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## EDITOR'S LETTER

At *The Positive Side*, we're always on the lookout for people living with HIV who want to share their stories. (Maybe that's you! If so, drop us a line at [contribute@positiveside.ca](mailto:contribute@positiveside.ca)). And we're constantly awestruck by the incredible people we meet. People from across the country of all ages, backgrounds and walks of life. People who speak candidly about their struggles and who—over time, with the right support—develop great resiliency.

In this issue, we profile two people who embody stunning resiliency. Both have experienced traumatic life events and have come out the other side more connected to themselves and their purpose. They're surviving and thriving—with creativity, conviction, compassion and humour.

Gareth Henry, whose playful grin graces the cover of this issue, came to Canada as a refugee. Having survived brutal homophobia in his native Jamaica, he has spent his entire adult life standing up for the rights of LGBTQ people around the world. In the past decade, he has helped hundreds of queer and trans people seek asylum. Don't miss "Life Saver," on page 10.

You'll also meet photographer and artist Gustavo Hannecke. After suffering the loss of his birth family when they disowned him for being gay and the loss of his lucrative job following the crash of the tech sector, life lost meaning for him. But Gustavo soon landed in a good place—in fact, a better place: "I decided to abandon my old ways of trying to satisfy social expectations. From that point onwards, I was going to be the person I dreamed of being when I was 22—a good person, an artist, a father, a partner." Read his inspiring story, "Now I Will Be Me," on page 27.

In "Something to Be Anal About" (pg. 14) CATIE's own Joseph van Veen talks openly about his experiences as a two-time survivor (HIV and cancer) and helps shine a light on a cancer we don't talk about enough. We are also proud to feature three Indigenous physicians who explore the question: What can Western medicine learn from Indigenous healing? (pg. 18). Also in this issue: learn to lead (pg. 4); real talk from and for poz women (pg. 6); and more.

This issue feels like it's been a long time coming, and so does spring. Enjoy them both!

—Debbie Koenig

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## THE POSITIVE SIDE

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## Leadership Can Be Learned!

Interested in building your leadership skills? Want to educate people about HIV and empower others living with the virus? If this sounds appealing—and you live in Ontario, B.C. or Quebec—you might want to check out the Positive Leadership Development Institute.

**Kath Webster** has the scoop.

In 2009 the Pacific AIDS Network (PAN) sent me to Ontario for a leadership training by and for people with HIV. The goal was for me to check it out and see if we might want to adopt a similar program in British Columbia. I loved it! The three-day Positive Leadership Development Institute (PLDI) was thought provoking, challenging and a safe space to learn and share with other people living with HIV. A truly valuable experience.

Right from the get-go, the trainers told the group: “Everyone in the room is HIV positive.” That was poignant, and as the days unfolded I realized how powerful it was to witness other people living with HIV stepping into leadership roles throughout the training. My confidence was boosted and it became clear to me that leadership is not only reserved for charismatic people with type-A personalities—it is something that can be learned.

I returned home with new leadership tools and motivation to develop a PLDI in B.C. Our funding grant proposals were successful, and once the PLDI launched, I was honoured to become a volunteer trainer.

The purpose of the training is to help participants realize their leadership potential and build their capacity to participate meaningfully in community life. It promotes the principles of GIPA (the greater involvement of people living with HIV/AIDS) and MEPA (the meaningful engagement of people living with HIV/AIDS) in programs and policy making. GIPA and MEPA are grounded in the universal rights of people living with

HIV to self-determination and to participate in decisions that directly affect our lives.

The PLDI consists of three intensive training modules; each one runs for three or four days. The first, Core Training, explores the question “Who am I as a leader?” The other two, Board Governance and Communication Skills, are optional for those who wish to do further training. There are also plans to add a fourth module this year, Mental Health First Aid, using curriculum from the Canadian Mental Health Association.

The main goals of the PLDI are for participants to:

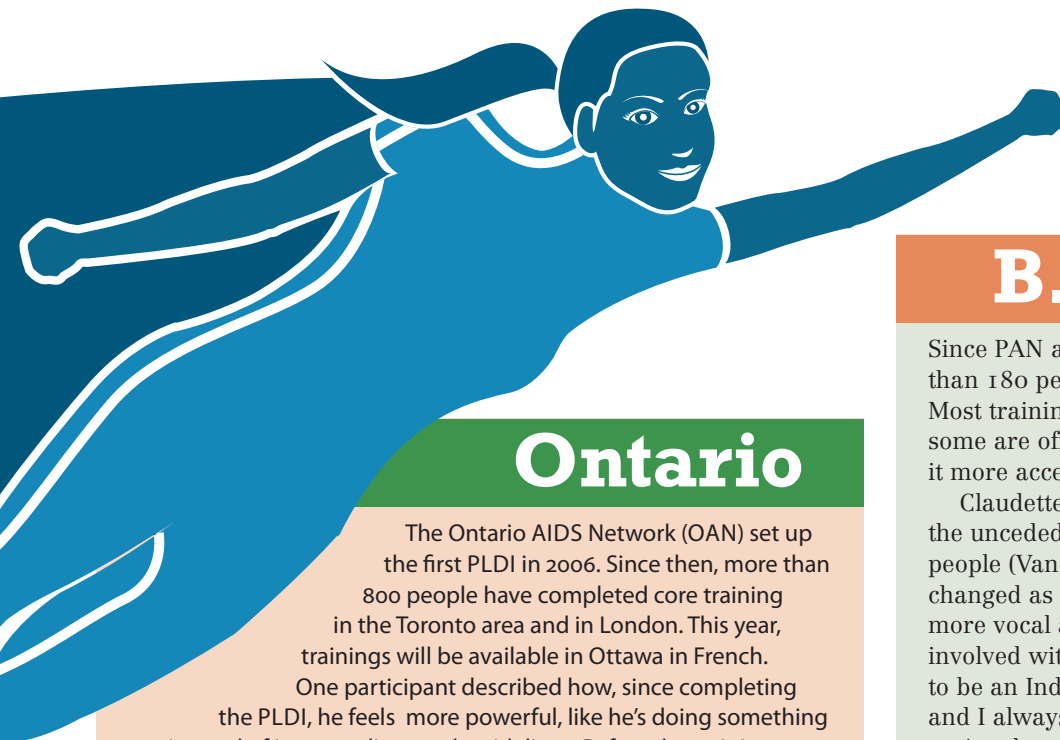
- identify their personal values and philosophy
- develop their leadership skills—giving and receiving feedback, public speaking and facilitation, among others
- gain knowledge and awareness of the HIV community

When a diverse group of people living with HIV comes together, peer support often happens naturally. The intensive training gives people an opportunity to explore their leadership skills in a safe and supportive way. As a result of the training, participants have reported increased self-esteem, being more assertive and feeling better equipped to cope with stigma. Graduates have gone on to use their leadership skills as board members of community organizations, peer researchers and much more.

PLDI trainings are now available in Ontario, B.C. and, most recently, Quebec—at no cost. +







## Ontario

The Ontario AIDS Network (OAN) set up the first PLDI in 2006. Since then, more than 800 people have completed core training in the Toronto area and in London. This year, trainings will be available in Ottawa in French.

One participant described how, since completing the PLDI, he feels more powerful, like he's doing something instead of just standing on the sidelines. Before the training, there was no way he would have ever done public speaking, whereas now he does it with confidence. Being in a room with 20 people with HIV from different walks of life opened his eyes to how the epidemic has changed. Another participant says that through the PLDI, she gained a better understanding of not only who she is but of who we are as a community and how powerful we are as leaders when we come together.

**To learn more or to apply, visit [oan.red/pldi](http://oan.red/pldi)**

## Quebec

In 2017, in partnership with the OAN and PAN, COCQ-SIDA (the Coalition of Quebec Community Organizations fighting HIV/AIDS) launched a PLDI in Montreal. COCQ-SIDA executive director Ken Monteith, who co-facilitates the trainings, says, "We are very excited to be adapting the PLDI into French and into the Quebec context. We hope that our graduates will leave with the confidence to take their place proudly in the HIV movement."

Monteith is proud of the way in which arts-based methods have been integrated into the training to help participants explore their strengths and challenges in creative ways. The Quebec team "draws on their own varied experiences of HIV using creativity to help participants discover and understand their own roles in the HIV community and beyond."

PLDI trainer Brigitte says: "I'm happy to be a part of this program because I see how our participants leave after the training—confident, luminous and motivated to change the world. Witnessing this is so inspiring and fulfilling."

**To learn more or to apply, visit [idlp.info](http://idlp.info)**

## B.C.

Since PAN adopted the PLDI in 2009, more than 180 people have taken the core training. Most trainings are held near Vancouver and some are offered in the B.C. Interior to make it more accessible to those from rural areas.

Claudette Cardinal, a Cree woman from the unceded territory of the Coast Salish people (Vancouver), says that she has changed as a result of the training: "I'm more vocal and assertive. I've become more involved with HIV organizations. I'm proud to be an Indigenous woman living with HIV and I always try to empower others."

Another participant, Al Hungershafer, says: "I am a proud graduate of the PLDI Training Program. It has had many significant and positive influences on my life, both within and outside of the HIV community. Core Leadership gave me a greater sense of self-confidence, Communication Skills greatly improved my ability to speak in front of groups, and Board Governance gave me a far better understanding of the roles and responsibilities of board members. These skills are extremely useful and can be easily applied to many aspects of my life."

**To learn more, visit [pacificaidnetwork.org](http://pacificaidnetwork.org) and click on "Training and Leadership" or call the PLDI manager at 604.569.1998.**

If you live outside of Ontario, B.C. and Quebec and don't have access to a PLDI, you might want to check with your local HIV organization to see if they have a speakers' bureau. Speakers' bureaus offer people living with HIV an opportunity to share their experiences and educate the public—at schools, universities, health centres, etc. In doing so, speakers challenge misconceptions and stigma.

Kath Webster has been active in the HIV community since her diagnosis more than 20 years ago. Among other adventures, she helped bring the PLDI to B.C. Kath lives happily on Salt Spring Island, B.C.

# Woman to Woman

If your best friend was diagnosed with HIV, what would you want her to know?

INTERVIEWS BY RONNILYN PUSTIL



**AYESHA**, 36  
Regina  
Diagnosed with HIV in 2014

First, I would thank her for confiding in me. I'd want her to know that her HIV wouldn't change anything between us. I would still love and respect her.

I would want her to know that whatever emotions she is feeling—shock, anger, sadness, shame—are natural and just temporary. They will go away. That's what happened to me and to most people I talk with after they are diagnosed. Eventually you come to terms with your diagnosis.

The more you learn about the virus, the less anxious you will be. When I was diagnosed I didn't know much about HIV and thought I would die quickly. I had lots of unanswered questions. After my husband and I came to Canada, CATIE helped a lot; we got so many resources from CATIE.

I would also want her to know that being diagnosed today is not how it was 30 years ago. Big advances have been made in HIV treatment. I would advise her to start treatment as soon as possible. The earlier you start, the

*"You can have sex, get married, have children. You can have it all."*

better for your health. But you have to stick with it—you have to take your pills daily as prescribed by your doctor. If you adhere to your treatment and have an undetectable viral load, you won't pass HIV to others.

It's going to be a bit challenging because taking your meds is a daily reminder that you have HIV, but in the long run it will be better for you. It becomes like having a chronic disease, which you manage by taking your pills. Eventually it will become routine. And you can live a long, healthy, fulfilling life.

I'd tell her that I would support her however I can, but she needs other support, too. A support group for people living with HIV will really help. They exist in almost every community. Being in a support group has helped me overcome my fears and anxiety. It helps me see that I'm not alone.

I learned that getting HIV is unfortunate but it does not mean I did something wrong. I am not ashamed anymore (though I do choose to keep it confidential because of discrimination and stigma). I am no longer angry or sad, as I know I can have a normal life. I realized anyone can get HIV regardless of their gender, ethnicity, religion or whether they're rich or poor.

Take time to breathe, take time for it to sink in. It's up to you to decide

who to tell. The people you tell might react in different ways. Disclosure is not easy.

Find something that helps you unwind and release stress and anxiety—meditation, exercise, listening to music, getting a massage—and do it. It's important to take good care of yourself. I wish I had had someone to tell me these things when I was diagnosed.

Finally, I would tell her about my situation: I am married to an HIV-negative man and am about to have a child. HIV has not kept me back. I wanted a family and that's what I'm getting. These days with HIV you don't have to be sick. You can have sex, you can get married, you can have children. You can have it all.



**ALEXANDRA DE KIEWIT**, 40  
Montreal  
Diagnosed with HIV in 2010

When I was first diagnosed, I thought my emotional and sexual life was over. Who would want an HIV-positive woman? I will always remember this one episode: I wanted to tell Pops that

I was HIV positive. Pops is a wonderful man who helped street youth, he was like a grandfather to me. The day I told him, he was with three of my friends. One of them, Caro, was one of those girls you wish you could be—gorgeous, radiant, with beautiful green eyes—you know, the type you envy.

After I told Pops, Caro came to see me and said, “You know, I have been living with HIV for the past 14 years.” WOW! I would have never thought that this woman could be HIV positive. It suddenly didn’t seem so big and scary!

*“No man has ever rejected me because of my HIV.”*

I have now been in a relationship for the past five years. Even before that, no man ever rejected me because of my HIV. So this is what I would tell my girlfriend: Life goes on! With medication and an undetectable viral load, the risk of transmission is zero. And if the person who wants you changes their mind because you have HIV, then they don’t deserve to be with you!

**JADE FARAJI, 54**  
Toronto  
Diagnosed with HIV in 1992

First, I would tell her: You are not alone. I would ask how she is doing, how she is taking the news of being diagnosed and how she feels. And then I would disclose my status to her if she doesn’t already know it.

I would give her some basic information on HIV and tell her where to access more resources—from doctors, clinics and women’s HIV organizations—to get as much information as she can, but not to overwhelm herself. If it becomes overwhelming, just take baby steps and take time to process it.

I would encourage her to talk to her doctor so she can understand what the virus is all about and find out what her CD4 count and viral load are. I would

encourage her to get some counselling and build a support network. And, of course, I’ll be here to support her if she needs anything.

I would want to tell her that she can live for so many years if she takes her meds. I’d tell her that sometimes people get tired of taking their meds every day and want to take a drug holiday, but I would encourage her not to do that. I almost died from a drug holiday.

I would talk to her about my own experiences living with HIV—how I got diagnosed, what it meant for me to go on treatment, and so on.

I would talk to her about how important it is to eat healthy, exercise, surround yourself with positive people and energy, make sure you don’t get stressed because that can affect your viral load and CD4 count, and just do things you like to do.

Some people pray, some people meditate, some do other things that make them feel grounded. What grounds me is connecting to nature. So I do a lot of camping and hiking. When I’m in the bush, in the middle of nowhere, I’m at peace. I would tell her: Find what grounds you and talk to someone when you feel sad. It will help you through stress or depression.



**MONICA HOPKINSON, 44**  
Calgary  
Diagnosed with HIV in 1994

If my best girlfriend were diagnosed with HIV, I would reassure her that she can still lead a normal life. That it is no longer a death sentence since HIV medications have come a long way. I’ve had no side effects or

problems with the medications I’m on now (three pills a day) and my viral load is undetectable.

I would want her to know that undetectable=untransmittable.

That she can still have children and a family. My first husband passed away and I have since remarried and had two children—one is 24 and the other is 15—both HIV negative.

That there are agencies out there where she can get information and support. My older sister was my biggest support when I was diagnosed. I told her right away. She’s been there for me through everything—when I

*“I am living my life like a healthy person. I don’t even think about the HIV that much. Yes, I have to take medications, but that’s it.”*

was taking care of my husband, when he passed away, and when I was in and out of the ER she drove from B.C. to be there for me.

I would tell my friend that she does not need to disclose to people until she is ready. When my first husband and I were first diagnosed, we lost a lot of friends because of stigma. After he passed away, I started going to the HIV organization here in Calgary and I started disclosing more. Then I started visiting schools and telling students my story.

I would tell my friend to take care of herself, take time for herself and, most of all, stay positive. I don’t look at HIV as a sickness. I am living my life like a healthy person. I don’t even think about the HIV that much. Yes, I have to take medications, but that’s it.

Last but not least, I would tell her that I will be there for her every step of the way, no matter what. +



# Stats that Might Stun You

These statistics are estimates, based on the latest data available at the time of publication.

Number of new HIV infections reported in the Philippines  
in 2007: **342**

Number of new HIV infections reported in the Philippines  
in 2017: **11,000+**

Percentage increase in 10 years: **3,147**

Where HIV ranks among eSwatini (formerly Swaziland)'s  
top 10 causes of death: **1**

eSwatini is the country with the world's highest prevalence rate of HIV.

Percentage of adults ages 15-49 living with HIV: **27.4**

Percentage of Jackson, Mississippi's population of gay, bisexual and other men who have sex with men  
(MSM) who are living with HIV: **40**

Percentage of people living with HIV in Jackson, Mississippi in 2016  
who were Black: **82.2**

Proportion of Black MSM in the U.S. who will be diagnosed with HIV  
in their lifetime if current trends continue: **1 in 2**

Proportion of Latino MSM: **1 in 4**

Proportion of white MSM: **1 in 11**

Percentage of people who received an HIV diagnosis in 2016 in the U.S.  
who were African American: **44**

(even though African Americans make up only 12% of the U.S. population)



In Canada, too, African, Caribbean and Black (ACB) people are over-represented among people living with HIV. In 2014, the percentage of people living with HIV in Canada who were African, Caribbean or Black: **16**  
(although ACB people make up only 2.5% of Canada's population)

ACB people are approximately **6 times** more likely to get HIV than other Canadians.  
(This is based on HIV rates in people from HIV-endemic countries so the numbers may in fact be higher.)

Indigenous people are approximately **2.7 times** more likely to get HIV than other Canadians.

Number of people worldwide who have been infected with HIV since the start of the epidemic: **70+ million**

Number of people living with HIV worldwide in 2017: **36.9 million**

Number of people living with HIV in Canada at the end of 2016: **63,100**

Percentage of people living with HIV globally that know their HIV status: **75**

Percentage of people with HIV in Canada that know their HIV status: **86**

Of those diagnosed with HIV in Canada, percentage on HIV treatment: **81**

Of those on HIV treatment, percentage that have a suppressed viral load (<200 copies/ml): **91**

Number of serodiscordant couples enrolled in the PARTNER study between September 2010 and May 2014: **1,166**

Each of these couples consisted of one HIV-negative partner and one HIV-positive partner on treatment who maintained a viral load <200 copies/ml. The number of times couples had condomless sex over the course of the study: **58,000+**

Number of HIV transmissions that occurred between those couples: **0**

Number of times serodiscordant couples—in which the HIV-positive partner was on treatment and maintained a viral load <200 copies/mL—enrolled in the follow-up PARTNER2 study had condomless sex over the course of the study: **76,991**

Number of HIV transmissions that occurred between those couples: **0**

The chance of passing HIV to a sex partner if you are on HIV treatment and have a suppressed or undetectable viral load: **0**

The above numbers come from the World Health Organization, UNAIDS, the Public Health Agency of Canada, the BC Centre for Excellence in HIV/AIDS, the Institute for Health Metrics and Evaluation, and the Canadian HIV/AIDS Black, African and Caribbean Network.



# Life Saver

Fueled by his commitment to social justice, **Gareth Henry** stands up for the rights of LGBTQ people around the world.

BY SARAH LISS

**F**or Gareth Henry, altruism is less a choice than a vocation—he’s perpetually, inevitably drawn to opportunities to help others. Gareth arrived in Toronto as a refugee in 2008, fleeing persecution and certain death as a prominent out gay man in his home country of Jamaica. Since then, he has committed himself to improving the lives of others. The 41-year-old activist and advocate has worked to connect members of marginalized groups with vital resources (at The 519, a community centre that advocates for LGBTQ people, and at Kids Help Phone) and he’s currently the director of programs and services at the Toronto People With AIDS Foundation (PWA). In 2009, he joined Rainbow Railroad—first as a volunteer and now as senior program officer—to help bring LGBTQ folks fleeing violence and persecution in their home countries to safety. Since then, he has worked with and supported more than 350 individuals from the Caribbean seek asylum in Canada, the U.S. and Europe.

While growing up in St. Mary, in northern Jamaica, Gareth started to feel compelled to care for others around the same time he was becoming aware that he was gay. That was in 1985, at the age of eight. “I’ll always remember that summer,” he recalls. “I was trying to locate myself, to find the space where I could be accepted.”

For a queer kid being raised in an intensely homophobic culture, that process of self-discovery was inflected with anxiety and confusion. Gareth describes watching a football coach in his community who was rumoured to be gay dodge items that were thrown at him as he walked to his office. “He was known as a *batty* man [Jamaican slang used to refer to a gay man]. My mom and stepdad would say, ‘Don’t become like him!’ People would warn, ‘Cross the street when you see him!

Don’t go close to him! Don’t let him touch you!’ I knew that wasn’t right,” Gareth says, “but I also didn’t want that to happen to me.”

For some, that roiling mix of homophobia and fear that Gareth experienced might spark an impulse to persecute other outsiders, but for Gareth, it fed his sense of social justice and responsibility. Even as his growing awareness of his own sexuality led him to turn inward, empathy prompted him to reach out. He noticed that this football coach who was painted as a pariah seemed to be a good person. “So I started to talk to him,” he says. “We never had much conversation, but I needed that to help normalize the experience for myself.”

Connection and belonging would not only become driving forces in

Gareth’s personal life, they would eventually provide the through line for his life’s work. As he was contending privately with his own sense of otherness, the young boy found solace and a sense of community in a somewhat implausible space: the church.

Religion was sacrosanct in his household. His mother and grandmother tried to “protect” him by sending him to church on Sundays *and* Saturdays. (“That’s a lot of Jesus!” he quips.) Though sermons about Sodom and Gomorrah might not seem particularly encouraging for a young queer kid, Gareth grew to love church because, he says, “it was a place I felt safe. Outside, people would call me names; in church, I didn’t hear that. I knew what to do: I would sing in the choir, I could quote scriptures!”

To be sure, the fire and brimstone gave him pause: “On the one side, it felt good to talk about Jesus and love, but then you’d hear the hate coming from the pulpit. How could these be the same people?” Even so, Gareth was tempted to get involved in ministry. For him, the essence of church was a commitment to loving and supporting people. “I loved taking missionary walks—going out in the street to find people in need. I loved helping people in the hospital. I loved seeing people happy. I was the little boy who’d leave

*“My job is to make sure people have access to what they need to live positively being positive.”*



school to lend a hand. Neighbours would call me to wash their dishes. My mom had such a hard time with me—she'd say, 'You need to say no!' But I couldn't. I always just wanted to help."

**G**areth's vague notions of becoming a minister persisted into his teens. After graduating from high school, he moved to the capital, Kingston, and enrolled in college. At 19, he made a connection that would change his life. While working in customer service for Jamaica's revenue department, he began chatting with a customer by the name of Gladstone Allen, with whom he quickly became friends. The two conversed in the coded, nuanced, subliminally loaded way common to kindred spirits who, for reasons of survival, keep their sexuality covert. Eventually, Gladstone invited Gareth to join him in the evenings to attend meetings with others who, like them, were outlaws of a certain kind.

The purpose of the organization that ran the meetings, Jamaica AIDS Support for Life (JASL), was to spread awareness and support people living with HIV. But practically speaking, as a safe haven in an inherently homophobic culture, it was also an oasis. "I walked into the space and saw men galore!" Gareth recalls. "I saw guys in dresses, butches.... I'd never seen so many people who were deemed to be different in one space."

Though he insists he's shy in most of his life, Gareth was utterly transformed by his exposure to the group. As he tells it, he had seen men "beaten, chopped and chased through the streets by angry mobs." He'd witnessed people around him suffering and wasting away from AIDS in silence, too terrified of HIV stigma to open up about their diagnoses. He'd heard about lesbians being subjected to corrective rapes, about friends who had lost their jobs and been abandoned by their families simply because of their sexuality or because of rumours that they were HIV-positive. Though he knew that attending these meetings might put him at risk—he'd be more easily identified as gay, more easily



"tainted" by negative gossip—Gareth was so moved by the work JASL was doing that he immediately signed on.

JASL's motto was simple: love, action and support. Every Tuesday, they would join together to sing what became their *de facto* theme song: Dionne Warwick's "That's What Friends Are For." "It would always bring the room to tears. It would motivate and inspire us that amidst such hate and violence and the uncertainty of whether or not we'd live to see the next day, we had each other, in that moment, in that space and time." Here is where he found his voice. He felt empowered to challenge the negativity that surrounded him and his peers. "I wanted to fight back and stand tall with my community."

Gareth signed up as a volunteer to visit people dying of AIDS in hospice. Before long, that volunteer position morphed into paid work. "I didn't know much about HIV," he recalls. "I didn't know anything" beyond rumours. But he quickly learned, thanks to his passion for the work and the careful mentorship of the man who hired him. "We were the only place of refuge for people with HIV," he says. "I'd see

40, 50 people walking into the office in very bad shape on a daily basis. It broke my heart, but I realized we were a beacon of hope for folks—they could come to us and talk and feel loved."

**B**y the late 1990s, the homophobia simmering in Jamaica had reached a boil: Anti-gay rhetoric was embedded in the lyrics of songs and in the political speeches of people running for office. Inciting violence toward sexual minorities was viewed as a viable way to appeal to the masses. Fuelled by a desire to push back against this onslaught of hatred, a group of men and women, most of whom were affiliated with JASL, came together and started an advocacy organization in 1998, which was housed at JASL. It was called the Jamaica Forum for Lesbians, All-Sexuals and Gays (J-FLAG)—and Gareth was eager to be a part of it.

"I was a kid and had no idea what was involved in building an organization," he says. "But I figured that if I was engaged and designed my own role, I could be part of it." He started out fetching coffee and water. "I became more and more involved and more and more excited. I realized, 'this is where I fit in.'" In 2004, Brian Williamson, J-FLAG's spokesperson, was murdered. Gareth stepped up to take over as the face and voice of the organization.

It's not that he was unaware that being a visible gay man in Jamaica put his life at risk. Within five years, 13 of his friends were killed as a result of hate-motivated attacks. But he was compelled to move forward, to believe, with almost religious fervour, that he could make a difference for himself and his peers. With J-FLAG, Gareth says, he found a sense of fulfillment akin to what he experienced at church. At university, he turned his attention to social work, to ensure that his professional path would dovetail with his personal passion.

But by 2007, his efforts to better the lives of LGBTQ people had made him a target. He was beaten repeatedly, once by four police officers, in front of



over 300 bystanders. Gareth went into hiding but couldn't escape the death threats, the violence and the fear that his next encounter with an unfriendly face would spell his demise. When he accepted that it was time to leave, his public profile was a boon: It was clear that Gareth's actions as an out gay man had put his life in jeopardy, and he was granted asylum in Canada as a refugee.

Gareth's mother followed four months later. And his sister and nieces arrived in 2012, after media reports about a petition he had launched against the Jamaican government resulted in people harassing his family members. "Neighbours put homophobic signs on their gates, the kids were bullied. I felt horrible. Because I chose to be my authentic self, those who love and care for me became victims of homophobia. Their lives were forever changed simply because they chose to love, rather than hate."

**T**o say Gareth views his work as a matter of life or death is no exaggeration. He is acutely aware of the stigma that can be associated with an HIV diagnosis. Two decades ago, when he first joined JASL, the situation at home was dire: "People were dying alone, at home. Sometimes people were afraid to leave our office because they were afraid they'd be seen. They'd worry about getting sick, about visiting a clinic." Many young people were wary of accessing vital services because they feared being spotted; the consequences could be deadly. "I had partners who died from AIDS because they were too ashamed to get care and support," Gareth says. He describes how he became a primary caregiver for Gladstone Allen, the dear friend who had initially introduced him to JASL. "We wound up living together, and he became unwell. He lost his job because he couldn't work. He didn't want to go out, he didn't want to go to the hospital."

"As he was dying," Gareth says, "he said, 'Whatever you do, don't get this, don't get AIDS. Promise me you won't let this happen to you.'" Gareth

couldn't make that promise. He had been assiduous about getting tested, but in April of 2003, Gareth had learned that he was HIV-positive. He had no remorse about his status, but he felt compelled to protect his friend.

*"My status did not change my life. It altered my perspective on the people around me."*

"I let him die peacefully and with the thought that I wouldn't have to go through the stigma, discrimination and hatred he went through."

From that moment on, he says, "I vowed I would never be ashamed to tell anyone who asks—I'm positive. My status did not change my life. It altered my perspective on the people around me."

**C**ertainly, being positive in Toronto in 2019 is leaps and bounds ahead of contemplating life with HIV in Jamaica in the late '90s—or even the early 2000s. Yet Gareth is cognizant of the subtle and not-so-subtle hierarchies that exist for those in need of support and resources. It's one thing to be a privileged, white, cisgender Canadian citizen with health coverage and family support; it's another to be a newcomer who doesn't speak English, a street-involved youth, an individual contending with precarious housing and employment. "My job is to make sure people have access to what they need to live positively being positive," Gareth says. "It's very difficult to keep your head above water. Sometimes the HIV stigma is so subtle, and in this day and age, it's horrific when I listen to a client talk about the difficulty they have accessing services in the city or

about not being able to disclose that they're positive. I want to continue to create awareness and to make sure we're doing whatever we can to hold people accountable."

Given the psychological and physical violence Gareth endured, the trauma of having to identify the bodies of loved ones, the psychological toll of ministering to ailing people as they face the end of their lives, it's hard to imagine where Gareth finds the personal resources to fuel such emotionally demanding work. He claims it's all about balance.

"I'm vigilant: I work hard at two jobs [PWA and Rainbow Railroad], and to keep up my life and relationship, every three months my partner and I pack our suitcases and go somewhere where we can do silly stuff and have cocktails on the beach." Self-care, he explains, is paramount. Still, beyond Gareth's regular getaways, he insists it's the work itself that gives him strength.

"Every so often, I ask myself whether this is what I should be doing," Gareth muses. "I think I've been involved in advocacy and activism since I was 20, so that's the last half of my life. And there's not one day where I've regretted it. My mother always said, 'You know, boy, you just can't say no.' When I tell someone no and they walk away, it pains my heart. There's a more nuanced way to engage with people. How can I inspire you to take ownership over your life? How can I inspire you to make change for yourself?"

"I know what it is to be at the bottom of the barrel and treated as an outcast," he adds. "No one deserves to be treated that way. If I can turn that around for one person a week, that makes me happy." +

Sarah Liss is a Toronto-based writer and editor whose work has appeared in *The Walrus*, *The Globe and Mail*, *The Hairpin*, *Hazlitt*, *Toronto Life* and *Maclean's*. She is also the author of *Army of Lovers*, a community history of the late artist, activist, impresario and queer civic hero Will Munro, published by Coach House Books.



# Something to be Anal About

Gay and bisexual men with HIV have high rates of anal cancer—yet we don't talk about it enough. Here's how one man survived a disease that may be highly preventable with the HPV vaccine and yearly screenings.

BY TIM MURPHY

ILLUSTRATION BY BENOIT TARDIF

**Joseph van Veen** is a two-time survivor. The events and membership coordinator at CATIE for the past decade, van Veen, 53, has lived with HIV for at least 32 years, developed heavy drug resistance and currently takes a total of seven drugs (some of them in the same pill) to maintain his undetectable viral load and stable CD4 count. “I’m a textbook long-term HIV survivor,” he jokes. “I’ve been on mono-, dual and triple therapy and got through the period when everyone else was dying.”

But he's also survived something else: anal cancer. Diagnosed in 2016, he underwent five weeks of chemotherapy and radiation treatment immediately thereafter to rid himself of the cancer, which has a 50 percent five-year survival rate max if caught and treated early. More bad news? Anal cancer rates are higher among people living with HIV. The rate is especially high among HIV-positive gay and bisexual men: approximately 100 times higher than in the general population. And despite effective HIV treatments, those rates are rising.

"The main cause of death among people with HIV is cancer, and the main cancer is anal," says Dr. Irving Salit, professor of medicine at the University of Toronto and the head of the HIV clinic at the Toronto General Hospital. He's been dealing with anal cancer in his HIV-positive patients for at least 18 years. He says that about 1 percent of his gay and bi male patients living with HIV have had a diagnosis of anal cancer, which is linked to strains 16 and 18 of HPV (human papillomavirus), which most sexually active people have been exposed to.

But now for the good news: Anal cancer is preventable—with regular screening (via yearly anal PAP smears and an exam called a high-resolution anoscopy, or at the very least digital exams) and with treatment or observation of precancerous growths. That's why, if you're living with HIV—especially if you are a gay or bisexual man or a transgender woman, or if you have had anal sex—it's so important to be screened regularly. If your healthcare provider can't or won't screen, you might want to find one who does!

Salit, in fact, is part of an ongoing large, multi-site study, called HPV-SAVE (HPV Screening and Vaccine Evaluation in Men Who Have Sex with Men), to determine whether treating or simply watching precancerous lesions is best for preventing anal cancer. It also aims to determine if subjects who get the HPV vaccine despite already having HPV receive additional protection against anal cancer. (To learn more, visit [www.hivnet.ubc.ca/clinical-trials/ctn292](http://www.hivnet.ubc.ca/clinical-trials/ctn292))

So far, says Salit, the study shows that "there's a real lack of knowledge about HPV and about HPV-associated conditions, especially cancer as a gay men's disease. Most of the men in the study who [initially] chose not to sign up for the screening...never really thought of anal cancer as linked to [the same HPV virus as] cervical cancer."

## AN UNUSUAL CASE

As for van Veen, his anal cancer presented in a fairly rare manner that regular internal anal screening would not have picked up: a skin tag on his inner butt cheek. "It's called the intragluteal cleft, but it's really just your ass crack," he says with a laugh. "The skin tag was itchy and bled sometimes on toilet paper." A gastroenterologist told him it was precancerous and referred him to Toronto's Princess Margaret Cancer Centre, where the tag and some of the area around it was surgically removed. But once biopsied, the tag turned out to be actual cancer—a very small tumour.

"It was the worst day of my life," recalls van Veen, who received the diagnosis with his husband, Bruce Edwards, a

speech and language pathologist whom he started dating in 2000. "You would think that getting an HIV diagnosis in 1986 would be, but back then I felt young and invincible. Now, thirty years later, I'm thinking, I'm not going to die from HIV but from something else. I didn't hear anything after the word *cancer*. It's good Bruce was there to take notes."

The couple then had a tough decision to make: Delay treatment until they returned from a much-anticipated, long-planned trip to Nicaragua or cancel the trip and start treatment right away. They chose the latter—and soon enough van Veen was taking time off work to embark on a super-aggressive treatment: a five-week course of radiation and during the first and fifth weeks, chemo (fluorouracil, or 5-FU), to preventively blast the site where the skin tag had been and his local lymph nodes as well.

"The first three weeks, I barely noticed anything was happening," he says. But then his radiation burns intensified to the point that having a bowel movement and wiping himself was excruciating. By his last day of radiation, right after Christmas, the burns were so raw and wet that when he sat down on some bedsheets naked, they stuck to his butt when he got up—and pulling them off was hellacious. "I thought, 'Wow, it's come to this—like pulling a kid's tongue off a frozen pole,'" van Veen recalls.

Remarkably, up to nearly that point, van Veen had insisted on walking daily the six kilometres to and from the treatment centre—even when he'd begun to lose control of his bowels and had to memorize the public washrooms along the route. He's no fragile flower; he completed an Ironman triathlon in 2003 and cycled 6,200 kilometres from Nairobi to Cape Town in 2004 to raise money for AIDS relief in Africa.

But by week 4 of treatment, "I finally said that I don't need to be the hero right now," he recalls. Thankfully, he was on a drug that kept his nausea to a minimum. He

## HIV & ANAL CANCER

- HIV infection increases the risk of anal cancer.
- In the general population, anal cancer rates are higher among women than men. But among people with HIV, rates are highest among gay, bisexual and other men who have sex with men (MSM).
- Anal cancer rates among HIV-positive MSM are roughly double those of HIV-negative MSM.
- Symptoms of anal cancer include bleeding, pain, masses or lumps, but sometimes anal cancer has no symptoms during the early stages. This is why, although there are currently no guidelines or protocols for screening anal cancer, experts like Salit say that screening is key.
- Treatment usually consists of radiation and chemotherapy or surgery.



“The single greatest risk for anal cancer in HIV-positive folks is smoking.”

napped frequently, applied creams to his buttocks and took pain meds amid the worst of things.

“My husband calls me a goal-oriented person,” he says. “As long as there’s a finish line, I have something to work toward. So I pushed through to the end of the treatment. I had moments of depression, and it was dehumanizing when I lost bowel control, but nothing was too overwhelming.”

### REDUCING RISK—AND BUSTING STIGMA

According to Salit, the single greatest risk for anal cancer—or, for that matter, all HPV-related cancers (cervical, vulvar, vaginal, penile, anal and cancers of the back of the throat)—in HIV-positive folks is smoking. In fact, 19 percent of cancers among people living with HIV in North America are likely caused by smoking, researchers published early this year in the journal *AIDS*, looking at data on more than 50,000 HIV-positive people over 15 years. If you are HIV-positive and smoke, one of the best things you can do as a preventive measure is quit smoking.

Beyond that, says Salit, a diet rich in antioxidants—with a focus on things like cruciferous vegetables (such as cauliflower, Brussels sprouts, broccoli) and green tea—may be protective. But he can’t stress enough the importance of screening. “This is a very serious cancer but it’s probably preventable, which is why it’s so important that HIV-positive gay and bi men and transgender women in particular talk to their providers about getting screened annually.”

He says that his study so far shows that many such folks thought they had been screened for anal cancer by their colonoscopy. Not so.

As for van Veen, he says that treatment severely affected his bowels and it took him up to eight months after he finished to fully recover his sphincter control, leading to a few embarrassing incidents. He wouldn’t wear adult diapers, though. “Pride, I guess,” he says. “I carried an extra pair of underwear with me instead.”

Since then, he’s thrown himself back into a busy life, with not just his 9-to-5 CATIE job but involvement in a local theatre, for which he is now directing a production of *Doubt: A Parable*, the John Patrick Shanley play that was

made into a movie starring Meryl Streep. He admits he hasn’t been able to get back to working out as intensely as he did before the treatment. But he and Bruce have started travelling again; recently, they visited Iceland and Croatia and soon they’ll hit Vietnam.

He’s honest about how having anal cancer can mess with one’s sexual identity and confidence as a gay man. “Anal sex has dropped off the radar because there was so much damage done and I still have some issues around bowel control,” he says.

Plus, he adds, there was stigma of having anal cancer. “We don’t talk about the cancers below the belt: penile, vaginal, anal.” He himself admits that he often would refrain from telling people what kind of cancer he had. Yet he also tried to break the stigma by blogging about his whole experience (at [jvanveen.blogspot.com](http://jvanveen.blogspot.com)). “I learned that we have to talk about these cancers,” he says. “I’m no David Sedaris, but I tried to keep the tone light and funny.”

For anyone diagnosed with anal cancer, he has this advice: “Remember that the treatment will end and you will heal. It’s not easy but it’s usually short.”

And, refreshingly bucking the common cliché, he says that having survived cancer has not imbued him with some keen new appreciation for life. “I already had that experience with HIV. That’s when I learned to live every day not as if it’s your last—but as if there is a tomorrow.” +

Tim Murphy is a Brooklyn-based novelist and journalist who has been reporting on HIV for 25 years and living with HIV for nearly 20. He has written extensively for *The New York Times*, *New York* magazine and *The Nation* and writes regularly for *POZ*, *thebody.com*, *HepMag*, *Impact* (the magazine of Lambda Legal) and other publications. He is the author of the New York City AIDS saga *Christodora* and the novel *Correspondents*, about the U.S. invasion of Iraq and its aftermath, out next year from Grove Atlantic. He watches *Paris Is Burning* over and over again.

## THE HPV CONNECTION

- HPV is the most common sexually transmitted infection (STI) worldwide. Most HPV infections go away within two years without causing problems.
- Of the 150 different types of HPV, only certain strains (especially 16 and 18) are associated with anal cancer.
- HPV is passed mainly through skin-to-skin contact during sex (oral, anal and vaginal). Condom use can reduce but not eliminate the risk of transmitting HPV during sex.
- In Canada, it is recommended that all children get vaccinated by age 12 to prevent HPV. Gay youth (over 9 years of age) and men who have sex with men should also get the HPV vaccine.







# What can Western medicine learn from Indigenous healing traditions?

By doctor and Indigenous healer **Lewis Mehl-Madrona**

ILLUSTRATION BY JESSICA DESMOULINS

Since the earliest days of the epidemic I have known and worked with people living with HIV/AIDS. I was a family physician in San Francisco before the virus was even identified as HIV and well into the contemporary times of effective antiretroviral drugs. In the early '80s, many of us had identified a terrifying disease that was stalking predominantly gay men. I remember encounters with the spirit of that disease being among the most frightening I have ever experienced. We struggled to make sense of what was happening.

People who are schooled in the biomedical approach to health (as I have been) frequently ask me how traditional healers treat specific diseases. I struggle to explain how traditional North American medicine more closely resembles Chinese medicine than contemporary biomedicine. Traditional Elders approach the person as an integrated whole. Health is restored through restoring balance among mind, body, spirit and community. Elders focus more on the person and how to restore harmony and balance for them, rather than treating the disease as it is defined by Western biomedicine.

The differences between traditional healing practices and biomedical medicine deserve highlighting. Traditional practices emphasize communication with spirit beings and direct requests for healing. This communication occurs

through prayer, song and ceremony. Additionally, one looks for areas of disharmony and imbalance within the external community, within the community of one's mind, and in the relationship with our bodies, the earth, the plant people, the animal people and all of creation. Healing is achieved through achieving balance and harmony in our many relationships. The approach to each person is different because each person is unique and has their own set of imbalances. By contrast, biomedicine generally looks for the one treatment that will benefit the highest number of people with a particular disease, such as HIV.

But the two approaches are not incompatible. Mi'qmaq Elder Albert Marshall, of Sydney, Nova Scotia, introduced the term *two-eyed seeing* to describe the idea that the Indigenous and scientific approaches can co-exist. Certainly, the scientific approach has made great headway with HIV—contemporary antiretroviral drugs are highly effective and have transformed the shape of the world of HIV. Nevertheless, the traditional approach still provides benefit to those who use it, above and beyond antiretrovirals.

My childhood was immersed in my grandmother's and great-grandmother's traditional healing practices. Despite my interest in science, I never doubted the validity and importance of how they lived and what they practiced to help members of their community get well.

## HIV IN INDIGENOUS COMMUNITIES

So, where are Indigenous communities today when it comes to HIV? Indigenous people are over-represented in the HIV epidemic in Canada: Although Indigenous people made up only 4.9 percent of the general population in 2016, they accounted for 9.6 percent of people living with HIV and 11.3 percent of the estimated 2,165 people in Canada who received an HIV diagnosis that year.

The challenge lies in getting people tested, encouraging them to get on HIV treatment and stay connected to care despite the many social factors that mitigate against doing so.

## SOCIAL ISSUES

The social factors that affect people's health are extremely important. For example, Indigenous people face more poverty, violence, stigma and discrimination, substance use, sexually transmitted infections and barriers to accessing healthcare services. They are also more likely to live in rural and remote areas. These factors can all increase people's vulnerability to HIV and act as barriers to accessing HIV care. An understanding of HIV vulnerability in Indigenous communities must begin with exploring these factors that have arisen from European colonization and the resulting atrocities of genocide, destruction of language and culture, the reserve system, residential schools and so on.

For many Indigenous people, accessing HIV treatment means having to face the stigma of going to a clinic where many of the staff are one's relatives or friends, which can deter people from getting treatment. A larger problem arises from the number of Indigenous people who migrate to urban areas or move on and off reserve, which can act as a barrier to healthcare. People can obtain provincial or territorial healthcare, but doing so requires a certain level of organization.

The chaos that poverty can create in a person's life can be astounding: How does one deal with bureaucracies without a safe place to keep their records? How does one get a health card or enter a healthcare system without a stable address? How does one schedule a doctor's appointment without a phone number where they can be reached? Many people do not know basic information about HIV transmission and infection, or how

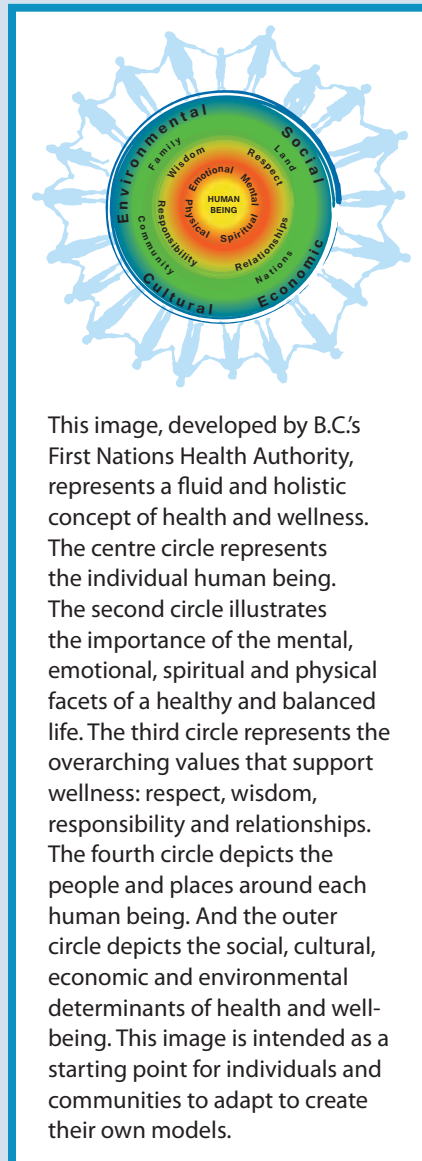
to avoid contracting the virus. They do not know how or where they would go to get tested.

Numerous studies, such as these, have shed light on the negative impacts that violence, discrimination and poverty can have on people's health, pointing to the need for HIV care to address these issues.

- Physician and researcher Reed Siemieniuk and his colleagues at the University of Calgary incorporated a domestic violence screening interview into their care of people living with HIV in southern Alberta. Of 853 patients, 34 percent reported abuse. Groups at higher risk for abuse included females, gay men and Indigenous people. The researchers found a connection between a history of domestic violence and delayed access to care, missed appointments and increased use of clinic resources such as social work and psychiatry.

### Domestic violence was associated with poorer outcomes for people living with HIV.

- A study of more than 1,400 women living with HIV in Canada found that **everyday incidents of racism made women less likely to access care**. These incidents included prejudiced comments from healthcare providers and disrespect for the women's cultural traditions. Angela Kaida, a senior author of the study and an associate researcher at the BC Centre for Excellence in HIV/AIDS, says that this finding emphasizes **the need for more peers to be involved in the planning and delivery of HIV services and the need for more culturally relevant services**.
- Sarah Flicker and her colleagues at York University supported Indigenous youth leaders to produce digital stories about HIV prevention. Their preliminary work showed how important it was for youth to tell their stories, which made **connections between HIV and structural violence**. They focused on the role of family and Elders, traditional sacred ideas about sexuality, education, reclaiming history, focusing upon strength, cosmology and overcoming addictions. In contrast to conventional public health messaging, the youth emphasized **indigeneity and decolonization as key strategies for health promotion**.
- Roberta Woodgate and her colleagues at the University of Manitoba interviewed young





Indigenous people living with HIV in Winnipeg. They found deeply interconnected social worlds that included abuse, trauma, being part of the child welfare system, lack of housing and hunger interwoven through the threads of these young people's lives. They concluded that **more effort needs to be paid to address the social determinants of health**. They highlighted how **stigma and discrimination prevent people living with HIV from easily accessing supports and health services**. Creative and culturally appropriate forms of outreach are key for reducing stigma and discrimination.

These studies, and Indigenous approaches to healing, can teach us how important it is to pay attention to the social determinants of health and provide culturally appropriate outreach and care for both Indigenous and non-Indigenous people living with HIV.

Here are two stories of people from my medical practice that further illustrate these ideas:

*Harold was a 17-year-old Indigenous man living in an urban youth shelter. He considered himself lucky to have a warm, dry place to sleep. Our medical residents were providing care to the adolescents who lived at the shelter. Harold had reluctantly allowed us to test him for HIV. When the test came back positive, he shrugged it off. It didn't mean anything to him. He didn't expect to live long anyway. His world consisted of figuring out where to sleep at night, how to avoid having sex with people he didn't like (unless they paid him or gave him weed), how to avoid being robbed or beaten, and how to get to school. The shelter had arranged for him to go to high school, where he was doing well. Harold didn't trust or believe much of what we had to say. He was quite fatalistic. We arranged free counselling for him with one of our social workers/therapists. Together they visualized a future for Harold where he took advantage of a training program in heating and air conditioning and made good money. It was strange for Harold to imagine a future beyond the next day. He would have had to return to his home reserve to receive supports other than the care we were providing, but he didn't want to do that because of the abuse he had been subjected to from his family and related to other broken relationships in the community.*

*Stephanie was a 25-year-old Mi'qmaq woman who had been addicted to heroin since she was 18 and had transitioned to opioid substitution therapy four months earlier. Her recovery was precarious due to her high levels of*

*anxiety, which she had managed previously with heroin. Funerals were more common for her than births—her friends were dying at an alarming rate. Stephanie was seeing us for healthcare because she wanted her buprenorphine. Otherwise, she wouldn't have come. Like Harold, she was fatalistic. Each day that she awoke, she was surprised to still be alive. Stephanie lived in a studio apartment, which she paid for by doing sex work. She didn't care if she had HIV or gave it to anyone. Her attitude was that it would serve them right to get infected for sleeping with her. She was angry at her situation. Her childhood had been spent on the reserve with a drug-addicted, alcohol-involved family. Stephanie was fiercely defensive of her friends and family, and to her chagrin, they kept dying. We convinced her to allow us to test her for HIV, and she was unconcerned with the results. She didn't expect to live much longer, though she occasionally aspired to have a child and a family. In typical Stephanie fashion, she said, "I'm running one fuck ahead of the grave, anyway. What do I care if I slip and fall in?"*



**Healing is achieved through balance and harmony in our many relationships.**

—Dr. Lewis Mehl-Madrona

These stories highlight the need to change the way our society thinks about HIV and about healthcare. While progress has been made in finding effective treatments and in disease prevention, those who suffer most sometimes receive the least

care. We need to speak to HIV treatment and prevention as an act of decolonization and find culturally supportive leaders and messages to reach those who are on the margins. Providing housing can go a long way to helping people start and stay on treatment. Providing easier access to healthcare and antiretroviral medication also makes a big difference, as does supporting activities that promote people's cultural practices. Involvement of Elders and traditional cultural wisdom keepers in health promotion efforts is also crucial. ✦

Dr. Lewis Mehl-Madrona completed medical school at Stanford University and trained in family medicine, psychiatry and clinical psychology. He worked in family medicine and psychiatry in Saskatoon and taught at the University of Saskatchewan. He works with Aboriginal communities to develop uniquely Aboriginal styles of healing and healthcare. His goal is to bring the wisdom of Indigenous peoples about healing into mainstream medicine and transform medicine and psychology through this wisdom coupled with European-derived narrative traditions. Dr. Mehl-Madrona currently teaches at the University of New England and practices medicine at the Eastern Maine Medical Center.



**I always encourage people to use their power, use their voice.**

I spend a minimum of 30 minutes with each patient, and sometimes up to two hours. I go to their homes when they need me to and I go to the hospital when they need me to. When you are able to do those things, you learn so much more about what somebody needs. And you become like a human to them, not just a doctor.

I don't do symptom management. I'm always asking, "Why are you having this symptom? Let's figure that out because in the long term that's going to be the most beneficial to you."

An appointment with a patient is like visiting. We talk about their health issues but I also spend time just listening to whatever they have to tell me. Say I'm with someone who has a chronic lung condition. I review their meds, but I always want to know what else is going on. There are all these details and if you let someone talk, you learn a lot—about their family life, their most intimate relationships. How are those doing? Do they have access to good things to eat? Are they fearful for their safety?

I think it would be best if physicians could take on clients really slowly, have time to go through their records, have time to sit with them. But you get into practice and you get thrown all these clients and you're expected to know everybody's life story. People get frustrated when you haven't read over their records. But when am I supposed to do that—on my own time when I'm at home with my child? There are expectations on either side that I think are sick because of the way the system is set up.

There are healers in our community who know a different way. They spend more time with people. There's also a spiritual component that is missing in mainstream medicine. The way that I combine Indigenous and mainstream healing practices (I do both of those things for myself, too) means that I can better understand what people need so I can connect them with those things.

#### **How do your patients respond?**

Some say, "Are you really a doctor?" I have a client who tells me every visit that he can't value enough the fact that I listen to him. He tells me stories and has valuable things to say and he wasn't being heard or validated by whoever was serving him previously. That's the case with many of my clients—they weren't being heard, so they weren't being helped.

One of the things we know is that it takes a community. First you have to know yourself really well, and then you can start to take care of others. When everyone is getting well, the community benefits.

#### **It sounds like the person-centred care you're talking about is important for all people.**

Lately I've been shying away from labels like Indigenous and non-Indigenous because we're all human beings.

**Dr. Samantha Boshart** is a family physician at the Chatham-Kent Community Health Centre on Walpole Island, in southwestern Ontario. Originally from London, Ontario, she is of Anishinaabe and German Mennonite descent from the eagle clan (*kinew dodem*) and a member of the Chippewas of the Thames First Nation.

**W**hat led you to combine Western and Indigenous approaches, to improve the health of your patients? And how do you do that?

I lived the first 30 years of my life with a certain worldview, exactly what the Western model wants you to see and believe. That was good because it taught me how to be a Western thinker and to use my brain to analyze, objectify, categorize and learn all these things that science offers. I learned to practice medicine in that way.

But during med school, I also started to learn about a different way of looking at the world. I sat with people and read and learned about a worldview that really connected with who I was as a person. As I started to understand more about this way of looking at the world and myself and human beings, I saw that there was this huge disconnect between what the Western model had taught me and my understanding of health and the truth. To reconcile the two is difficult.

For example, one straightforward concept is that if you aren't well, you shouldn't care for other people. If you're not a well human and you're not connected to your spirit and your self and you're not taking care of yourself, how can you care for others? But in the Western model of medicine, as a resident you sometimes work 36 hours straight, and the system is dominated by authority and hierarchy. After you graduate from med school and set up practice, you're expected to take on thousands of patients (the average number for a family doctor is 2,000). The average length of time a doctor spends with a client is about 10 minutes. It's a very high-stress, demanding job, yet we're expected to provide healing and a path for people to get well. The model for how we do it doesn't really allow for that.

Since I started working approximately four years ago, I have never had a 10-minute interaction with a patient.

We're all of the same species and we all have the same basic needs. We are all connected to creation—to the land, to the sun, to everything. This approach is not unique to one group or one place. For us to be really well as human beings, the approach should be the same for all human beings: recognizing that we all have physical capacity, an intellect, emotions and a spirit. Those things need to be valued and addressed equally.

**In some ways what you're talking about is more about how healthcare providers and institutions can adjust their practices, but is there anything that people can do to foster a more holistic approach to their own healthcare?**

I always encourage people to use their power, use their voice. When they don't feel right about the care they're receiving or they don't feel heard, they need to say something directly to the provider. If they want to go beyond that, and they're feeling courageous enough, they can go to the management and HR of organizations. Everyone has a voice and we only create change when we use our voice and our truth.

People complain to their families and friends—"My doctor's terrible," "I didn't feel heard." Who says that to their doctor? Why can't doctors be held accountable for the shitty care they provide? Because no one is telling them. Doctors are given so much power and they're not held accountable. People almost never complain to the person doing the harm. People are afraid but everyone has to work on their own fear. You have a voice, please use it.

I want to know if you don't like my care. Healthcare is a publicly funded system, so the public has a say. If you're using your voice laterally—to your family or friends or community—but not upwards, I would challenge people to be honest with their providers about how they feel about their care. The provider might react poorly because they might feel triggered but it's still important. The truth is always felt. They'll feel it in their heart and their spirit and they'll think about it.

As doctors, we're not better or stronger. Our goal as doctors is to help people.



**It is very important to decolonize healthcare practices.**

to establish who we are in every context but in the healthcare setting I feel it is even more essential. Colonization has caused many wounds. It is thus very important to decolonize even healthcare practices. I think this vignette highlights this quite eloquently:

Many Indigenous patients we saw in clinic were experiencing deeply distressing situations—poverty, threats to their own and to their loved ones' safety and well-being, chronic pain, children in foster care. Western medicine does not address many of these issues, which are a big part of a person's health and well-being. Some

patients lamented a lack of access to ceremony and to traditional medicines like cedar or sweet grass, as they now lived far from their home communities and elders. They were invited to share in smudging as part of their primary care appointment and they were presented with medicines to take with them for ceremonial use at home.

The reasons for these individuals' suffering and their disconnection from traditional healing practices and materials can be traced to colonization and current systemic racism. Many people with HIV share this terrible legacy. The use of ceremony and the provision of traditional medicines is a deeply symbolic, highly powerful gesture of decolonization and healing.

Many non-Indigenous people with HIV have also lived through their own traumatic experiences or are dealing with distressing situations and need help finding their paths to healing.

**Dr. Melinda Fowler-Woods** is a Metis/Mi'kmaq woman who grew up in Newfoundland and Labrador. She is the director of Ongomiizwin Education at the University of Manitoba's Indigenous Institute of Health and Healing and is currently developing a framework to integrate traditional medicines into the federal correctional system.

I am an Indigenous physician. I am trained in Western medicine and I am training in traditional medicine with my teacher Kathy Bird. I am an Indigenous person first and foremost and I feel a void when it comes to being able to adequately provide care for my Indigenous peoples without gaining further knowledge about our Indigenous ways of healing. As I am on my journey to understanding more about who I am as an Indigenous person, I realize others are on their own journey as well. It is very important



# STRONG MEDICINE

A film by and for Indigenous people living with HIV.



Many Indigenous people living with HIV understand how Indigenous knowledge and culture can support and enhance the use of Western medicines used to treat HIV. In the film *Strong Medicine*, eight Indigenous people tell their story about living with HIV. They encourage others to get tested, start HIV treatment early if they test positive, stay on treatment and connect with their culture. Here are some of their words:

“When I look at anybody who’s struggling in their life, I ask myself, ‘What brought this human being to this point in their life?’ I try to remove judgment and just observe them. I think the doctors that have had the most impact on my life have shown concern about not only my physical well-being but my mental well-being, my emotional well-being and have asked me, ‘How are you doing in your life? What other support are you seeking in your healthcare? What keeps you healthy? What are some of the self-care things that you’re doing for yourself?’ Just a sincere interest in me as a human being.”

“My diagnosis was a life-changing moment for me, because up until that point I felt disconnected from my own community. I felt very disconnected from my culture, even though I speak my language. I’m fluent in my Anishinaabe language, but I felt there was something missing... Because I felt so alone when I was first diagnosed, and scared, I began praying. It really helped me to make that connection to my Creator... the prayers really helped, and I began learning more about connecting back to my culture.”

“When I was diagnosed, I was lost and confused... I was sad. I was lonely. I was depressed. I was suicidal. Almost everything in the dark. I switched. The spiritual people, the healing people, they brought light in my life. They brought my life back down to earth.”

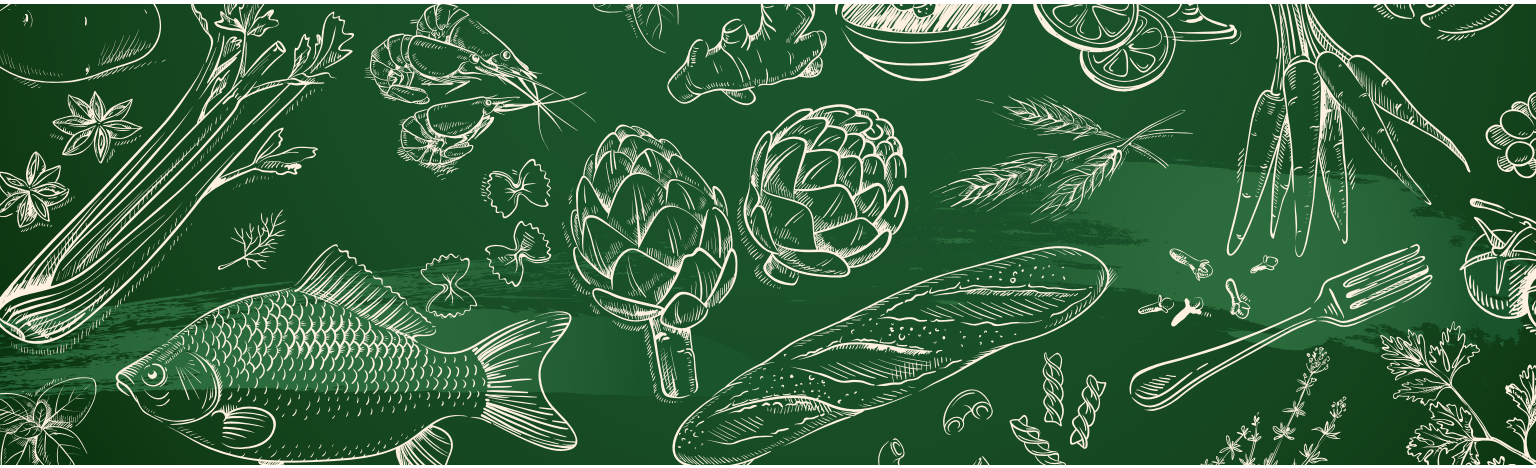
“There are people who have been living with HIV for longer than 27 years that I look up to and respect, and they were activists long before me. But there [are new] generations coming in, people newly living with HIV and they need us, who have been around for a while, to show that we’re alive! And we’re healthy and we’re happy.”

“People living with HIV/AIDS, they need their meds absolutely but they also need to keep their spirituality, to keep their spirit alive.”

You can watch the 27-minute video for free at [www.catie.ca/strong-medicine](http://www.catie.ca/strong-medicine)

If you want to host a screening in your community or at an organization you’re affiliated with, you can order a free DVD screening kit from the CATIE Ordering Centre: call 1.800.263.1638 or go to [orders.catie.ca/book/strong-medicine-screening-kit](http://orders.catie.ca/book/strong-medicine-screening-kit)





# Ask the Dietitian

**Annie Tsang** answers some commonly asked questions about nutrition.

**D**ietitians are important members of your HIV care team. They can recommend meal plans that are tailored just for you. Here's B.C. dietitian Annie Tsang on how you can use food to optimize your health.

## Do I have to follow a specific diet after being diagnosed with HIV?

There is no one specific diet recommended for all people living with HIV. Each person's nutritional needs are unique—they depend on the medications you are taking; your CD4 count; other health conditions you may have, such as diabetes or cardiovascular disease; and factors like whether you are underweight, overweight or at a healthy weight.

If your health is stable and other health conditions are under control, these general guidelines can help you maintain a healthy immune system:

- **Increase your vegetable and fruit intake.** Or if you already eat plenty of fruits and vegetables, keep it up!
- If you're not vegetarian or vegan, **eat fatty fish**—such as salmon,

sardines, herring, albacore tuna, anchovies or rainbow trout—twice weekly.

- **Eat foods that contain phyto-nutrients** (nutrients found in fruits, vegetables and other plant-based foods) **and omega-3 fatty acids** (in fatty fish and flax seeds) as they can help reduce inflammation in the body. (For more on anti-inflammatory diets and recipe ideas, see “Calming the Flames” in the Winter 2016 issue of *The Positive Side*, at [positiveside.ca](http://positiveside.ca)).
- **Take a daily multivitamin and a vitamin D supplement containing 1000-2000 IU.** Several studies have found that people living with HIV tend to have lower-than-ideal levels of vitamin D in their blood. Although you can get vitamin D from sunlight and fortified foods, the surest way to get enough is by taking a supplement.
- **Choose calcium-rich foods**—dairy products or calcium-fortified foods and beverages. This will help protect your bones and muscles.

- **Stay well hydrated** by drinking water and other non-alcoholic and decaffeinated drinks.

## Should I take supplements to help boost my immune system and energy?

Besides a multivitamin and vitamin D supplement, most people with HIV can obtain all of their nutrients through food.

People living with HIV (including people who are on HIV treatment and have no symptoms) generally have greater energy requirements than the general population, but foods such as whole grains and brown rice are excellent sources of B vitamins, which can help with energy. If you are wondering about vitamin B<sub>12</sub> supplements, be sure to check with your doctor before starting this or any other supplement.

Since diminished bone density is more common among people living with HIV, your doctor might advise you to take a calcium supplement if you don't consume enough of this mineral through your diet. Be aware that

this supplement can interact with certain HIV meds, such as dolutegravir (Tivicay, also in Juluca and Triumeq), raltegravir (Isentress), Genvoya, Stribild and Odefsey.

Let your pharmacist know which meds and supplements you are taking so he or she can advise you on how and when to take them. To avoid interactions, you may need to take your calcium supplement and HIV meds separately.

### **I heard that protein is important for me. How do I make sure I'm getting enough?**

Protein is indeed a very important nutrient. It helps to promote cell formation in our organs, build muscle mass and maintain a healthy immune system. You can get enough protein from your diet alone, even if you are a vegetarian or vegan. In general, a 10 percent increase in energy requirement is recommended for people living with HIV, to ensure a healthy weight and prevent muscle wasting. (Although muscle wasting occurs much more rarely than it used to due to improvements in HIV treatment, it does occur, especially in people who are diagnosed late.)

Speak with a dietitian to help determine the amount of protein that is right for you. A dietitian can take into consideration your food preferences when helping you obtain an adequate daily intake. Excellent sources of protein include lean meat or fish, eggs, tofu, dairy products, nuts and seeds.

### **I'm on a budget. Any tips on how I can eat healthy without breaking the bank? I can't afford to buy fresh meat and fresh fruits and vegetables every week.**

You don't have to eat only fresh foods to stay healthy. Canned foods, such as canned salmon, vegetables and legumes, can also be good options. Frozen fruits and veggies are also nutritious.

One idea is to stock up on non-perishable foods that are healthy when they go on sale. Although canned foods are sometimes high in sodium, you can always give them a good rinse or prepare the dish without adding extra salt or sauce.

## HOW DO I FIND A DIETITIAN?

Some health centres and doctors' offices offer dietitian services for free. If yours doesn't and you have private health insurance, check to see if your health plan covers dietitian services.

To find a dietitian in your province or territory, check out the Dietitians of Canada website at [www.dietitians.ca](http://www.dietitians.ca). Click on "Your Health," then "Find a Dietitian."

### **I also have diabetes and high cholesterol. Should I restrict what I eat to help manage them?**

You might need to adjust your food choices. In general, I would recommend having protein and healthy fat (e.g., from olive oil, nuts, seeds, avocado) with all of your meals and snacks to help stabilize your blood sugar. While refined carbohydrates (such as white bread, white rice, soft drinks and potato chips) can spike your blood sugar in a short time, protein and fat can help slow down that spike. Eating smaller, more frequent meals and snacks and combining protein/fat can help manage your blood sugar.

As for high cholesterol, consider eating more plant-based proteins (nuts, seeds, lentils, legumes) and less red meat. Consuming foods high in soluble fibre (such as oats, beans and barley) can also help lower your cholesterol level.

### **What if my HIV meds make me nauseous or give me diarrhea?**

Be sure to let your doctor know. Many people don't experience nausea or diarrhea as a result of the newer HIV drugs, but if you do, these side effects will most likely go away on their own in a short time. If not, you may be able to manage them with an over-the-counter medication.

Dietary strategies might also help you manage your symptoms. For example, ginger candies or ginger

tea/ginger ale might help with your nausea. You can also try eating bland foods, such as soda crackers, to help calm your stomach. As for diarrhea, if it is related to HIV treatment and needs to be managed with medication, food might not help much. Regardless, your dietitian can always review your diet with you. If you have diarrhea, drink lots of fluids and consider replenishing your electrolytes. You can try sport drinks or coconut water. For a more budget-friendly option, you can also add a pinch of salt to your water to replenish sodium and eat bananas to replenish your potassium.

### **Is there anything else I should be mindful of?**

Food safety is important for everyone, but it can be even more important for people with HIV. Wash your hands thoroughly before meals and keep your cooking surfaces clean. Try to limit the amount of raw fish and unpasteurized food products you eat. Ensure that all meats are fully cooked and refrigerate leftovers within two hours. For more on food safety, check out [www.healthlinkbc.ca/healthlinkbc-files/easy-food-safety](http://www.healthlinkbc.ca/healthlinkbc-files/easy-food-safety)

Remember: Moderation is key! As long as you are eating healthy most of the time, don't beat yourself up if you want to indulge once in a while. +



Annie Tsang is a dietitian who is registered with the College of Dietitians of British Columbia and Dietitians of Canada. She has extensive experience working with clients who have HIV, hepatitis C, eating disorders, cancer and mental health issues.

# Now I Will Be Me

After a personal breakthrough, photographer and digital artist **Gustavo Hannecke** models passion, openness and authenticity.

BY JENNIFER MCPHEE

Argentine-born artist Gustavo Hannecke's photographs tend to capture tender, happy moments and the beauty of the natural world. His digital art is more introspective and tells more complicated tales, often about his journey through life as an HIV-positive gay man. If this sounds like a contradiction, it's not. "My soul tries to come out in every photo or piece of art that I produce," Gustavo says. "And it's full of happiness and beauty and hurt and stories about the complexity of human feelings that I don't avoid but rather embrace, to express in my art."

**G**ustavo was born in Salta, Argentina, in a house his grandfather built, which included a darkroom. He comes by his work honestly, with four generations of photographers on his father's side and a long lineage of artists on both his mother's and father's sides. Growing up surrounded by art and his extended family, with whom he took trips to the beautiful countryside, Gustavo started photographing the people, pets and nature around him from a young age. Food was also a big part of his family life and he learned the art of cooking from his mother, grandmother and great-grandmother.



*Opening Skies,*  
Salta Province, Argentina, 2004



**Self-Portrait, 1982**

**F**or much of his early life, Gustavo tried to conform to his family's religious values. His father was a Baptist pastor and church life conditioned Gustavo to believe that being gay was a sin. "I remember my mother saying things like 'I'd rather die than have a gay son,'" he says. During Gustavo's late teenage years and in his early 20s, Argentina's right-wing military dictatorship abducted and killed tens of thousands of students, union leaders, intellectuals and anyone suspected of holding progressive beliefs. During this time, gay people were also imprisoned and killed.

Even in this oppressive atmosphere, Gustavo began to explore his sexuality in secret, using photography as a way to express himself. He took this self-portrait when he was 22. After completing a bachelor's degree in math and physics at the National University of Salta, with a promising career in teaching and science, he started developing a sense of himself as an independent person. "I began to discover my own body as a source of not guilt but beauty," he says. "I like this photo not because it's me as much as because of the composition and soul of it."

At the same time, Gustavo continued to struggle with societal and religious expectations. While pursuing a second degree in applied physics (solar energy), he worked as an assistant professor of physics, which gave him the opportunity to travel across Argentina and to Chile, Bolivia and Peru.



**Family photo, 1984**

Five generations of Hanneckes at Gustavo's great-grandmother's house in the rain forest. From left to right: Gustavo holding his first son, Gustavo's mother, wife, great-grandmother and grandmother.







**“We are all in the same boat. We are all equals and we all deserve the same respect and love.”**

In 1983 he began dating the woman who would become his wife and the mother of his three children. “My nature was gay, but I loved her and she loved me, and I tried to follow the religious teachings,” Gustavo says. “Back then, society was telling me that I was defective for being gay and that I was supposed to get cured and do the right thing. I did it with a good heart and good intentions. My wife and I had several good years together.” Their second child, a girl, was born in 1986 and died after birth due to a genetic deficiency. “I was convinced that it was God punishing me because I was secretly having gay sex.”

**T**his composition (*at left*) represents Gustavo’s conflict and search for balance. He is reaching up toward an onion and knife, which represent family, because, Gustavo says, food and cooking are synonymous with family in Latin America. At the same time, the onion causes tears. “My family is the source of who I am but also the source of crying and suffering, almost killing me with values that contradict my sexuality,” he explains. In this image, he is naked, exposed, on his toes above the water, trying not to drown. At the same time, he is holding onto himself and surviving. “That was my life for a long time and I wanted to express those feelings.”

After their third child was born, Gustavo and his wife immigrated to Canada in 1992 and settled in Ottawa to give their children a better life. Meanwhile, he was having extramarital sex with men. Suspecting that he might have HIV (a suspicion that was confirmed when he was diagnosed in 1999), Gustavo pushed himself to earn as much money as possible to leave to his children in case he died young. At one point, he was making \$400,000 a year working in the high-tech telecommunications sector, a job that required constant travel and long hours.

Although the job gave Gustavo the opportunity to travel across North America and stay in glamorous hotels, air travel after 9/11 became “a horror show,” with long delays caused by heightened security. The constant travel under these conditions was impacting Gustavo’s health. He recalls lying on the floor of Boston’s Logan International Airport in the midst of the anthrax attacks that followed 9/11, feeling like he was about to die. Soon after, he decided to take a break from his job and avoid travel so he could recuperate.

But when he was ready to return to work in 2002, the tech industry had crashed and he couldn’t find a job. The longer he was unemployed, the harder it became to make ends meet. He ended up moving in with his partner, his first serious relationship with a man (his marriage had ended few years earlier). He started to fall into a deep depression, and this put a strain on their relationship, which began to sour. Shortly after, in December, 2003, his sister died of complications from diabetes. The following day his father suffered a heart attack. Gustavo returned to Argentina to deal with the family crisis.

Still living with his partner in Ottawa, he decided to tell his family that he was gay. “It wasn’t acceptable to them. They disowned me. That trip was the last time I saw or talked to them. Those were the darkest days of my life,” he says. To top it off, he was taking the HIV drug Sustiva, which causes severe depression and suicidal thoughts in some people. On May 10, 2004, Gustavo attempted to end his own life.

“I wasn’t super sad,” he says. “Just numb. Life had lost meaning.”

While staying in the psychiatric ward of the Ottawa Civic Hospital under police watch, Gustavo had an epiphany: “I decided to abandon my old ways of trying to satisfy social expectations—meaning religious values, job

‘success’ and making money. From that point onwards, I was going to be the person I dreamed of being when I was 22—a good person, an artist, a father, a partner. Something transformed inside of me. I said, ‘Fuck it all. Now I will be me.’”

**G**ustavo describes his HIV and suicide attempt as true salvation because he finally got the help he needed to feel like a whole person again. This healing process continued as he met and began to support other people living with HIV through a new job offering peer support and art therapy at the AIDS Committee of Ottawa.

After he came out to his family, Gustavo’s mother had formally disowned him in an email that compared him to prostitutes and thieves. Ironically, in his new job, he met people

**“I’ve learned that there is no value in holding on too long to sorrow and bitterness because I can spend that time enjoying life.”**

who were prostitutes and people who had committed crimes. “But instead of hate, I just felt love for my HIV peers,” he says. “We are all in the same boat. We are all equals and we all deserve the same respect and love.”

While working at the AIDS Committee of Ottawa, Gustavo created *Our Way Through*, a booklet of uplifting portraits and short personal stories that sought to break down stigma by presenting his clients as real, beautiful humans. The organizers of the International AIDS Conference saw the booklet and asked him to be part of an exhibit of portraits at the 2006 conference in Toronto.

Gustavo agreed on one condition: that they pay for all the participants to attend the week-long event. “And so they did,” he says.



**G**ustavo’s lipodystrophy, a side effect of the HIV drugs he was taking, left him with well-defined muscles because his surface body fat was gone. He is also yoga-flexible and artistically creative. “All together, this makes me the best life-drawing model in town (humility aside),” he jokes. “Who could have known that at 50-ish I would be such a hot thing when I was supposed to be dead 10 years before?”

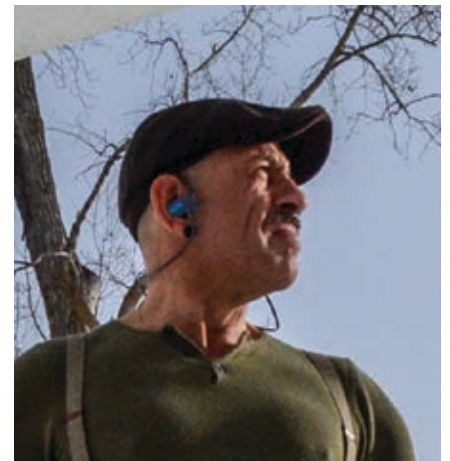
Gustavo parted ways with the AIDS Committee of Ottawa in 2007. To some

extent, he continues his HIV work (his design was selected in 2016 for a yet-to-be-constructed AIDS memorial in Ottawa) and volunteers at the Ottawa General Hospital with new patients of Hispanic background. But, today, he earns his living working as a model mainly for art students at Algonquin College and the Ottawa School of the Arts, and his main artistic focus is his photography. Family and friends are also important to him, and he has a good relationship with his two sons—whom he describes as “Canadian with a Latin flare” and his daughters-in-law and grandchildren.

Has he lived an interesting life? “I have certainly lived through a lot—good times and bad times. I’ve learned that there is no value in holding on too long to sorrow and bitterness because I can spend that time enjoying life. So far, it has been a fulfilling journey. It’s been rich for sure, but I don’t recommend trying it at home without supervision.” +

Jennifer McPhee is a Toronto-based writer who contributes regularly to *The Positive Side*.

To see more of Gustavo Hannecke’s photography and art, visit <http://gustavo1960.ca>.



## CONTRIBUTE

Want to share your story in *The Positive Side*? Send your name, where you live and 150 words describing your story to [contribute@positiveside.ca](mailto:contribute@positiveside.ca). We prefer email, but you can also mail your contribution to our office. (We will not return originals; please send a copy.) No calls, please. We will contact those people whose stories we are considering for inclusion. Contributions will appear in print and online. We can use a pseudonym to protect your identity. We do not accept poetry and we do not promote commercial products or services. The full contribution policy is available at [www.positiveside.ca](http://www.positiveside.ca) or by calling 1.800.263.1638.

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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.

CATIE in good faith provides information resources to help people living with HIV who wish to manage their own health care in partnership with their care providers. Information accessed through or published or provided by CATIE, however, is not to be considered medical advice. We do not recommend or advocate particular treatments and we urge users to consult as broad a range of sources as possible.

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