U=U
What does it mean for you?

Stigma stings
3 women face it head-on

Impact statements
Race + criminality in the media

INQUIRING MIND
Ian Bradley-Perrin on pop culture, AIDS activism and humanizing healthcare
Looking for HIV and Hep C services near you?

Healthcare, counselling and support are closer than you think.

Find HIV and hepatitis C services near you.
EDITOR’S LETTER

For most people, an HIV diagnosis marks a turning point they’ll never forget. Many clearly recall the shock, fear, worry: What will people think? How will it affect my relationships? For some, it’s not as big a deal, but everyone—whether it was yesterday or 30 years ago—remembers the moment.

Looking back, you might wish you had known then what you know now—that life goes on, that meds aren’t the nightmare they once were, that you’d still be you. Who could have imagined that science would one day show that if one’s HIV is undetectable, you don’t pass it on to your sex partners! We celebrate this in the opening article “U=U.”

In this issue, we ask two people living with HIV: “What is the one thing you wish you had known when first diagnosed?” Brittany and Tyler share their wisdom on page 6. If you are struggling with your diagnosis, we hope their insights reassure you; if you’re a long-term survivor, hopefully it will give you pause to reflect on how far you’ve come.

So, what helps with the journey? What we keep hearing from PS readers is that it’s all about getting connected—to other people with HIV, support, community.

When activist Ian Bradley-Perrin, who graces the cover, was diagnosed in 2010 he was already well versed in HIV and working in the field, so the news wasn’t exactly earth-shattering. But because he had supportive people in his life and a strong sense of community, he describes that turning point as a “magical moment” when everything came together (see profile by Sarah Liss on page 8).

That is not to say that there aren’t real challenges. Despite huge progress on the scientific front, stigma remains all too real. Kath Webster speaks to three women about their stigma stories (page 18) and Sané Dube investigates how the criminalization of HIV non-disclosure impacts African, Caribbean and Black communities in Canada (page 14).

We hope you enjoy this summer issue of The Positive Side! And we hope that PS plays a small part in keeping you connected to the diverse people living with HIV.

We always love hearing from you. Do you have feedback on this issue? A topic you’d like to read about? A story to share? Get in touch: dkoenig@catie.ca

—Debbie Koenig
The evidence is in:
If you are HIV+, take treatment and maintain an undetectable viral load, you can have sex knowing that you won’t pass HIV to your sex partner. In short, when HIV is undetectable, it’s untransmittable.

How can I make this work for me?
You can make this HIV prevention strategy work for you by taking your HIV treatment as prescribed and seeing your healthcare provider regularly. Your ongoing healthcare should include blood tests to check your viral load and ensure that it remains undetectable.

Wait until you have had at least two consecutive undetectable viral load test results before depending on this strategy.

To make this strategy keep working for you, adherence is key. If you have trouble taking your HIV medications every day, don’t be afraid to ask for help from your doctor, pharmacist and/or peer counsellor.

If your viral load does not become undetectable or if it becomes detectable again, this can increase the risk of transmission. In that case, you may need to use other prevention strategies, such as condoms, until your viral load becomes undetectable.

What about other STIs?
Maintaining an undetectable viral load can prevent HIV transmission but it does not prevent the transmission of other sexually transmitted infections (STIs), such as chlamydia, gonorrhea and syphilis. However, condoms can reduce the risk of many STIs, so you might want to use HIV treatment and condoms.

What is an undetectable viral load?
Viral load refers to the amount of HIV in the blood of a person living with HIV. HIV treatment can reduce the amount of HIV in the blood to a level too low to be measured by a viral load test. At that point, a person’s viral load is said to be undetectable. For most people, this occurs after taking HIV treatment for three to six months.

Having an undetectable viral load does not mean you are cured of HIV. The virus is still in the body. If you stop taking HIV treatment or miss too many doses, HIV will start replicating again and the viral load will once again become detectable.

What are the benefits of having an undetectable viral load?
We now know that it’s good for your health: Starting treatment as soon as possible after becoming HIV positive decreases a person’s risk of developing serious illnesses and allows people to live long, healthy lives. Having an undetectable viral load can also prevent HIV transmission.

How do I know if I’m undetectable?
The only way to know is to have regular viral load tests. If your viral load becomes detectable again, there may be a risk of HIV transmission. An ongoing detectable viral load may also indicate that your HIV treatment is no longer working properly. If your viral load becomes detectable, talk to your doctor.

How can I know that maintaining an undetectable viral load prevents the sexual transmission of HIV?
A significant body of research has been accumulating over the years. In 2016, the final findings from two large
All of us here at CATIE, and indeed around the world, are celebrating the most significant development in the HIV world since the advent of effective combination therapy 20 years ago. The “fabulousness” of this news cannot be overstated. With or without a condom, if you’re undetectable you won’t pass along HIV! This is an absolute game-changer and those who live with HIV can proudly share this information.

—Laurie Edmiston, Executive Director of CATIE

international studies—PARTNER and HPTN 052—were published. These studies showed that not a single HIV transmission occurred between serodiscordant sexual partners when the partner living with HIV was on treatment and had an undetectable viral load.

As Dr. Myron Cohen, the principal investigator of HPTN 052, stated: “We now have 10,000 person years of follow-up with zero transmissions from people who are suppressed.”

As a result, we can confidently say that when a person taking antiretroviral treatment maintains an undetectable viral load, they do not transmit HIV to their sex partners.

The Prevention Access Campaign—an international coalition of HIV advocates, activists and researchers who are spreading the word that undetectable HIV is untransmittable—has turned this scientific evidence into a simple message: U=U. Researchers from all the major treatment as prevention studies have endorsed it. (To read the endorsements, go to preventionaccess.org/consensus.)

I spent 21 years stigmatizing myself while trying to provide a positive front in my work with people living with HIV. I feel somewhat hypocritical because while fighting against stigma and discrimination, I perceived HIV as making me damaged goods, dirty and less than. I lived in fear of transmitting HIV and built walls to keep others out.

U=U has impacted me to my very soul. I am now aware that I am much more than a virus. I can look forward to meaningful relationships with others and opening my heart.

—Tom, Bonny River, NB

I am an HIV-positive woman. I have known for a long time, through consultations with HIV specialists, that I was not able to transmit the virus. This has given me a sense of relief when having condomless sex. The scientific proof makes me feel optimistic about stigma changing. It is an enormous move forward in normalizing people living with HIV, as we will no longer be marginalized. Through education, the public will respond to HIV in a more supportive manner and the quality of life for me and the HIV community will improve.

—Anonymous, Montreal

It took us too long to disseminate the findings of the PARTNER study. We were not simply cautious in our messaging regarding this transformative research, we were silent. Why did it take people with HIV and the organizations that represent us so long to get the U=U message out? Some thoughts: deep-rooted stigma against people with HIV; paternalism in our organizations and the alignment of ASOs with an under-informed government agenda, held in place through diminishing funding; and a disengaged, less scientifically literate national PHA movement that seems prepared to settle for the status quo in HIV.

—Darien, Toronto

This research is wonderful but many people are not aware that U=U. We need more education and we need to deal with the social stigma of HIV before the positive impacts of U=U can be widely felt. Despite all the research, the stigma is still there—not just in serodiscordant relationships but also in society.

I am in a long-term relationship and I’ve been undetectable for three years, but many women with HIV are fearful of being criminalized for not disclosing their HIV status. We still have lots of work to do before we can fully enjoy the benefits of U=U.

—Madhuri, Calgary

[Ed’s note: U=U has not yet had an impact on HIV laws in Canada. A person living with HIV in Canada still has a legal duty to disclose their HIV status to a sex partner before: (1) sex (vaginal or anal) without a condom; and (2) sex (vaginal or anal) with a condom unless you have a low viral load (less than 1,500 copies/ml). It is not clear how the law applies to oral sex.]

As an activist and as a person living with HIV who is privileged to have access to life-saving treatments and good healthcare, U=U is something I embrace and celebrate. U=U has presented people with HIV with even more reason to demand universal access to treatment and healthcare. As part of the North American U=U Steering Committee, I have connected with peers and activists across the globe to advance this important message locally and globally. As a member of the Canadian Positive People Network, it is my hope that our network can further explore how we can spread awareness of U=U—among poz folks, within the HIV sector, and with public health, government and the general public.

—Christian Hui, Toronto
What is the one thing you wish you had known when you were first diagnosed with HIV?

And, what advice would you have for someone newly diagnosed?

Interviews by Ronni Lyn Pustil

BRITTANY CAMERON, 31
Peterborough, Ontario
People living with HIV engagement worker, PARN
Diagnosed with HIV: 2006, at 36 weeks pregnant

I wish I had known that it would be OK.
That I wasn’t the first HIV-positive woman to give birth, and I wouldn’t be the last. That HIV-positive women can and do have HIV-negative babies. That one day, advocating for women with HIV to have babies would become a passion of mine and I would inspire other positive women to have babies of their own.

I wish someone had identified the unique challenges I would face as a woman and mother living with HIV in a rural area.

“I wish someone had identified the unique challenges I would face as a woman and mother living with HIV in a rural area.”

I wish I had known that HIV would drive a passion in me so strong that I would be inspired to build my leadership skills, be willing to share my status publicly and challenge oppression. Being diagnosed with HIV changed my life, but in a positive way, allowing me to feel alive again.

Before my diagnosis, I had no drive, no passion and no real goals or dreams. HIV gave me something to fight for, a sense of purpose, people to love, a community that welcomed me with open arms.

ADVICE:
Life goes on. One day you may look back and realize that having HIV changed your life for the better.

HIV doesn’t define you. You define you. You can have HIV and still have an amazing life.

Take the meds. As much as we dislike taking medications every day, they will help keep you alive.

Reach out. You deserve support. Nobody should live in silence and isolation.

Know that you are not alone. There are many positive people out there waiting to support you. Get connected and engaged. Engagement leads to community, and community can help give you a sense of purpose and keep you going.
Find your voice. Don’t be afraid to advocate for your needs.

Be gentle with yourself. You need to take care of you. Value yourself. Be your own best friend.

TYLER S. CUDDAHY, 31
Burnaby, B.C.
Board member, Positive Living BC; peer support worker
Diagnosed with HIV: 2006

December 4, 2006, I remember it vividly. At 10:30 am I arrived at work, at YouthCO, and settled in before slowly walking over to the office of the support program worker, Brandy. We had arranged that she would accompany me to get my HIV test result that day.

We made our way to what was known as The Centre (the Bute Street Clinic). I was happy that Paul, one of the street nurses there who I had built a professional relationship with, was going to tell me my results.

At 11:15 am, I was in the room with Brandy and Paul, feeling very nervous and bouncing my right knee like I do in these kinds of situations. Paul turned to his computer and started punching in information. I tried to reassure myself, “I am going to pass this with flying colours.” But, really, I knew I was going to be positive.

Six months earlier, I had been in a relationship with a man who straight-up told me from the moment we met that he was HIV positive. I told him, “I volunteer with an HIV organization, so I’m OK. Thanks for being so honest with me.” One day I decided to be the bottom and that’s when I knew that I had become positive.

Before Paul could tell me my result, I saw the computer screen. I was ready to bolt. “You’re HIV positive,” he said in a way that didn’t make it seem so negative. I looked at Brandy—she was tearing up. I was supposed to be the one crying but I just sat there and said, “OK, let’s go now. Thank you for telling me.” I didn’t want to be in that room anymore.

I wish I had known then that it is possible to live well with HIV! That the key is to take my medications every day so I feel fine, and to have people around me who understand and respect me, without judging me because I have HIV.

When I told people I was HIV positive, a lot of my so-called friends turned against me. That really hurt. I wish I had realized that they weren’t my true friends in the first place.

Lucky for me, I was already hooked up with YouthCO, which offers HIV and hep C services to youth in BC. (At 18, I had become hep C positive and got involved in the mentorship program. Luckily, I was able to clear the virus without taking any hep C treatment.)

Looking back at my life I feel like I’ve had a lot of negative things happen to me: hep C, then HIV... I am also someone who identifies as transgender, which comes with its own set of challenges.

But I am proud to deliver HIV services, to have been on the board of directors for YouthCO, the Hepatitis C Council of BC and Positive Living BC. And I volunteer with AIDS Vancouver Holiday Grocery because I get to be Miss Claus!

ADVICE:
It’s not going to be the end of the world. Don’t think that your life is going to end, because it’s not. It’s not like it was back in the ’80s and early ’90s when people were dying. We’re more advanced in the way that we can take care of people living with HIV. Start taking HIV medication as soon as you can because it’s going to help you live longer.
Your Nostalgia Is Killing Me

Activist Ian Bradley-Perrin on how romanticizing the past can obscure the present.

By Sarah Liss

Photograph by Laura Wilson
About five years ago, pop culture saw a flood of what can only be described as AIDS nostalgia. The catalyst wasn’t immediately apparent. Was it generational curiosity? Retro fetishism? Had enough time passed to transform the real trauma of the deadly ignorance, stigma, inaction and grief of the 1980s and early ’90s into, well, entertainment—or at least something more suited to mass consumption?

Regardless of the motivation, narratives rooted in the crisis years of the epidemic were ubiquitous: How to Survive a Plague, American journalist David France’s documentary take on the origins of ACT UP, came out in 2012 and was nominated for a host of awards; theatrical remounts of The Normal Heart and Angels in America, plays that premiered in 1985 and 1993, respectively, sprung up in smallish and bigger theatres around North America; a high-profile HBO adaptation of The Normal Heart, starring Julia Roberts and Mark Ruffalo, premiered in 2014.

The recurring images from these works—pale figures wasting away, riddled with Kaposi’s sarcoma lesions—resonated in ways both eerily familiar and curiously foreign. Here were sights and memories from the past, shown in a way that was disconnected from the current reality of living with HIV. Here was a spectacle to be witnessed from a distance and relegated to the annals of history. It was hard not to be left with the sense that you were watching a story that had ended years earlier, a battle that had been won, a fight that was no longer necessary.

For Ian Bradley-Perrin, now 27, that message didn’t sit well. At the time, he was living and working in Montreal, where he was studying at Concordia University and working with AIDS Community Care Montreal. To him, the reverent fixation on the history of both the disease and its nascent community was directly undermining a wider discussion of the reality of what it means to live with a positive diagnosis today—and undercutting the vital work being done in the 21st century.

“Ian’s response, created in collaboration with artist Vincent Chevalier (and inspired, at least in part, by “bitchy conversations with friends,” he says), was a clever, cheeky and striking contribution to the posterVIRUS campaign organized by Toronto’s AIDS Action Now! in November 2013.

Their piece, titled “Your Nostalgia is Killing Me,” features that wry line, emphatically rendered in bright-yellow, drop-shadowed letters, against the backdrop of a computer-illustrated bedroom. Keith Haring and General Idea graphics serve as wallpaper; visual ephemera from the ’80s—ACT UP reproductions, Therese Frare’s famous photo of mourners at a patient’s bedside, promotional images for the films Philadelphia and Blue—are presented as teenybopper posters, plastered on the wall like pin-ups.

It was a bold comment on how romanticizing the past can obscure present priorities and impede real action. But not everyone read it that way. For many, especially those who’d lived through those crisis years, the poster was a lightning rod. On social media, older activists attacked Ian and Vincent for what they perceived as undermining or dismissing the lived experience of survivors, calling them “stupid fucking brats” and accusing them, among other things, of committing “a little Oedipal murder.”

“It became really clear to me that there was this generational divide among people living with HIV, where younger people and older people interpreted the poster differently,” Ian says. He was struck, he notes, by how different generational experiences of HIV are from one another and he felt compelled to investigate that difference.
It was personal, political, historical,” he continues. “That combination of factors is what my work is now, and what it has always been.”

The posterVIRUS clash was a particularly heated and visible example of Ian’s activist work, but it was far from his first foray into challenging the dominant paradigm. A lifelong critical thinker, Ian can trace the origins of his militant consciousness back to his time as a high school student in Oakville, Ontario, a well-heeled suburb of Toronto.

It was in his teens that the seeds of his current interest in the intersections of public health and marginalized communities were planted. In 2007, during Ian’s final year of high school, he began dating his first boyfriend, who was grappling with addiction and mental health issues and struggling to find ongoing care and treatment.

Through the lens of first love, Ian’s eyes were opened to the shortcomings in the Canadian healthcare system—the dearth of detox, addictions and recovery services, and the challenges of finding a therapist for someone struggling with serious mental health needs. In a time of crisis, the only option seemed to be to go to the emergency room. “I was watching the outer limits of what was possible in Canada for healthcare,” he says.

After a brief stint out west, he enrolled at Concordia University and moved to Montreal in 2008. Once there, he discovered a passion for excavating and interrogating the past. “Like many people from Oakville, I was initially planning to be a doctor or a lawyer. But I soon realized the way science programs are set up is dehumanizing and impersonal. I felt like there was an immense amount that I needed to learn before I could do what I wanted to do—and history is the way that you learn about the world. What has brought us to this point? What have people done in the past? It’s everything.”

Ian’s true epiphany came during a first-year course in which he was reading a primary text about public health responses to the Black Plague pandemic in the 1300s. When learning about the ordinances instituted by the state to control communities, somehow, he says, the relationship between medicine, health and social control “just clicked,” and he realized what he wanted to do with his future.

For Ian, the personal may always have been political, but in terms of his own health, the political became personal as well. Sometime during his first or second summer of university, he says, he was back home with his parents, and in a haze of smoking weed and watching movies, when he stumbled upon Mike Nichols’ HBO adaptation of Angels in America. At the time, he says, he was yearning for a sense of connection and place.

Through the miniseries, Ian began to grasp the history of protest and politics and tragedy he’d inherited as a member of the LGBTQ community.

“I was born in an age and a place that AIDS wasn’t really part of,” he explains. “It was something I learned about in sex-ed, but I was seven in 1996. I think I remember seeing a headline about HAART (highly active antiretroviral therapy) becoming available, but that would be my first memory. I don’t really remember the early years of the epidemic. I had to rediscover that later on. For people who lived through that time, you can never forget it, but if you didn’t live through it, I believe it’s impossible to ever fully understand what it was like.”

After watching Angels in America—a work, he notes, he’s now more critical of—he began investigating HIV through an academic lens, embarking on a student project to conduct oral histories with people living with HIV and, eventually, forging ties with Montreal’s queer activist scene through happenings like Radical Queer Semaine. Thanks to those relationships, he says, when he tested positive for HIV in 2010, the experience wasn’t “earth-shattering.”

“I had supportive people who were easy to talk to. They were able to make jokes about it and talk about it over tea, or go partying with me if I wanted to. Within a few months, it seemed, I found friends with whom I finally felt a sense of shared understanding, I found an activist community, and I found a personal connection to something I was already interested in. It was one of those magical moments where everything sort of came together and suddenly the course of my life was clear.”

Even with some medical hiccups—bouts of PCP and tuberculosis, a staggeringly high viral load (3.5 million) and dwindling CD4 count (100) before he started Atripla in 2010—Ian embraced this clarity of purpose with gusto. He completed his undergrad work in 2012 and began volunteering with AIDS Community Care Montreal in 2013, doing fundraising and various other tasks. He’d become enamoured of the posterVIRUS campaign the previous year and drew inspiration from the unapologetic messages espoused by its participants. “I still have Mikiki Burino’s ‘I party. I bareback. I’m positive. I’m responsible’ poster hanging outside my bedroom door,” he says. “I
thought it was brilliant, even if I didn’t entirely understand it at first.”

Ian channelled that fiery energy into further studies at Concordia, using the ACT UP Oral History Project (a collection of interviews with members of ACT UP New York) to examine the roles of class and gender in treatment activism. “I looked at that moment when AIDS activists took up the necessary but also limited medicalized approach to their own condition, when they were like, ‘We need pills in bodies,’” he says. “Who were the people who got involved in that process? How was that defined by class and how did that shape policy?”

Those issues are also at the heart of the work he’s been immersed in since he completed his master’s degree in 2015. Ian is now a doctoral candidate at Columbia University, where his work focuses on the complicated role of the pharmaceutical industry in AIDS activism and treatment.

“Drugs got developed, which is great, but what does it mean for AIDS activists to have given community assent to these companies? Why is it now that there cannot be a single fucking Pride parade without Pfizer all over the place? Why do AIDS service organizations around the world rely on having to beg for money from pharmaceutical companies to survive?”

Beyond his dissertation, Ian has devoted time to grassroots organizing within Columbia itself. In the spring of 2016, realizing that he hadn’t been paid for the past eight months of his work as a teaching assistant, he rallied his colleagues to push for a union. It was, he says, a brutal struggle, but “we won 1,600 to 600.” And even though the U.S. National Labor Relations Board ruled last August that Ian and his fellow grad students at private universities are employees with the right to collective bargaining, the university is still challenging the outcome.

The fight, it seems, is never over. But even as Ian immerses himself in meaningful work—grappling with the insidious criminalization of HIV, contemplating the potentially coercive measures undertaken by the state to further decrease new infections, continuing to push for unionization—he remains focused on the future, while surveying the past.

“Disease is everywhere. Are we aiming to create the conditions in which people can live with HIV—or any other disability or illness that requires medical attention—with dignity? What should our goals be as a society? Are we aiming to get back to zero? Or are we aiming to ensure that people can live dignified lives with all of the messy realities that life entails?”

“The future for me is humanizing healthcare and our collective approach to health,” Ian says, his voice full of hope. “It’s not about being perfect, it’s about dealing with whatever happens.”

Sarah Liss is the senior editor of Reader’s Digest Canada and a Toronto-based writer 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, which was published in 2013 by Coach House Books.
The landscape of HIV prevention, treatment and care has changed drastically since the virus was first discovered in 1983. Even in the past decade, there have been tremendous advances in HIV research, arguably more so than for any other infectious disease. While all research furthers our understanding of how to respond to the virus, certain studies have had a particularly powerful impact. Some have influenced policies and programs and services for people living with HIV, while others have contributed to reducing HIV-related stigma and breaking down the divide between HIV-positive and -negative people.

Here we take a quick tour through some of the most influential findings of the past 10 years.

Treatment as prevention

At the 2006 International AIDS Conference in Toronto, the HIV community was introduced to the concept of “HIV treatment as prevention”—the idea that increasing the number of people living with HIV who are on treatment can reduce the number of HIV transmissions. Dr. Julio Montaner, director of the BC Centre for Excellence in HIV/AIDS and the driving force behind this concept, published a paper entitled “The case for expanding access to highly active antiretroviral therapy to curb the growth of the HIV epidemic” to coincide with the conference. In it, Montaner and colleagues summarized the research findings supporting treatment as prevention, including preliminary results from B.C., where new HIV diagnoses had decreased following a large increase in the number of people on HIV treatment.

It wasn’t until 2010 that Montaner and his colleagues would publish their full findings: Between 1996 and 2009 the number of people on antiretroviral therapy (ART) had increased by more than 500% and the number of new HIV diagnoses had dropped by 50%. While the findings were not yet conclusive evidence that treatment as prevention works—because other interventions, such as needle exchanges and Vancouver’s supervised injection site likely played an important role in the decrease—the seed was sown. Treatment as prevention is now a household name for those working in the world of HIV and it has had an undeniably profound impact on HIV policy and programs, both in Canada and internationally.

The HIV care cascade

As the idea of treatment as prevention began gathering momentum, there was uncertainty about exactly how it should be brought to bear on the ground. While there were global calls to scale-up testing and treatment, there were also concerns that some people might be coerced into getting tested and treated for HIV. The emergence of the HIV care cascade, a concept first widely disseminated in a paper by Edward Gardner and colleagues in 2011, offered insights into how treatment as prevention could be implemented.

The HIV care cascade concept highlights the fact that efforts to fully realize the health and prevention benefits of HIV treatment will fail unless they go beyond simply improving access to testing and treatment. The researchers estimated that only 19% of people living with HIV in the United States had achieved an undetectable viral load. This wasn’t only because of gaps in testing and treatment but also due to deficiencies in HIV care—including linking people to care after their diagnosis, retaining people in care, and supporting people to stay on and adhere to their HIV medications. A visual model of this series of steps—from HIV testing to engaging in care and starting treatment to achieving an undetectable viral load—became known as the HIV care cascade.
Policies are emerging that put the cascade at its centre, such as UNAIDS’ ambitious 90-90-90 strategy, which calls for 90% of people living with HIV to be diagnosed, 90% of diagnosed people to be on treatment, and 90% of people on treatment to achieve viral suppression (or have an undetectable viral load) by the year 2020.

**HPTN 052 and PARTNER**

The interest and excitement in using ART to reduce HIV transmissions first peaked with the release of the “Swiss Statement” in 2008. It declared that HIV-positive people with an undetectable viral load have a negligible to non-existent risk of passing HIV as long as they have been undetectable for at least six months, are adherent to ART, receive regular care and have no other sexually transmitted infections.

While some applauded the statement, others were critical of it due to the lack of evidence supporting its position. But fast-forward to a few years later: Compelling evidence arrived in the form of HPTN 052 and PARTNER. The landmark HPTN 052 study found that ART reduced the risk of HIV transmission by 96% among heterosexual serodiscordant couples, with no HIV transmissions occurring when the HIV-positive partner’s viral load was undetectable. Findings from the PARTNER study came to a similar conclusion for both gay male and straight serodiscordant couples, with no HIV transmissions occurring when the HIV-positive partner’s viral load was undetectable despite more than 58,000 condomless sex acts.

New consensus statements are now emerging, including that of the “Undetectable=Untransmittable” campaign, providing important guidance for people who want to use ART and an undetectable viral load as a prevention strategy.

**Strategic timing of antiretroviral treatment (START)**

With so much focus on the use of treatment as prevention, it is important that the primary purpose of ART not be forgotten—improving the health of people living with HIV. In the past decade, as we have learned more about the importance of starting treatment early for HIV prevention, evidence has also demonstrated its importance for one’s health. In turn, treatment guidelines have gradually changed to recommend that people start treatment sooner after diagnosis.

The first guidelines recommending treatment as soon as possible after diagnosis, regardless of CD4 count, were released in the U.S. in 2012, despite the lack of conclusive evidence of a health benefit at the time. In 2015, the START study filled this evidence gap with its finding that starting treatment when your CD4 count is greater than 500 significantly reduces the risk of serious infections, cancer and death. Starting treatment early is also associated with improved quality of life. What’s more, the vast majority of people who started treatment early did not experience serious side effects. With the evidence in, many other guidelines have followed suit to recommend starting treatment as soon as possible after diagnosis.

**CAPRISA 004 and iPrEx**

At the 2010 International AIDS Conference in Vienna, the presentation of the CAPRISA 004 study results received a standing ovation. The ongoing use of ART in HIV-negative people, a concept known as pre-exposure prophylaxis (PrEP), was shown to work for the first time. While various types of PrEP may eventually become available, the CAPRISA 004 strategy involved the use of a vaginal gel (containing the antiretroviral drug tenofovir) before and after sex. It was found to reduce the risk of HIV infection among women by 39%.

The excitement generated by CAPRISA quickly grew with the release of the iPrEx findings later that same year. The iPrEx study found that the use of a daily pill sold as Truvada reduced the risk of HIV by 44% among HIV-negative men who have sex with men. Impressively, the level of HIV protection was over 90% among those who used the pill consistently. A series of other PrEP studies released in the following years showed that the daily pill also worked for people at risk of HIV infection through vaginal sex and sharing needles.

While the vaginal gel remains unavailable, the use of a daily pill (Truvada) to prevent HIV infection has been approved by Health Canada and endorsed by the World Health Organization. Efforts are now underway to make this pill more available to people who need it.

James Wilton is an epidemiologist at the Ontario HIV Treatment Network (OHTN) who previously worked as CATIE’s Biomedical Science of HIV Prevention Coordinator for six years.

What do people living with HIV have to say about the game-changing discovery that undetectable means uninfectious? Find out in “U = U: What does it mean to you?” on page 5.
“In a word, it’s dehumanizing.” Robert Bardston is talking about media coverage of HIV non-disclosure cases. I’ve spent the past couple of months engaged in a series of poignant, inspiring and sometimes-heartbreaking conversations about the criminalization of HIV non-disclosure. I am trying to understand how mainstream media stories on the issue impact African, Caribbean and Black (ACB) people across the country. Robert and I are speaking on the phone—miles stretch between his Medicine Hat and my Toronto. It’s early and the sleep is still working its way out of his voice.

He lets out a weighty sigh and continues: “It’s dehumanizing to see yourself branded as deviant in the public eye, especially through the media.” Robert, an HIV activist and co-chair of the Canadian HIV/AIDS Black, African and Caribbean Network (CHABAC), has lived with the virus since 1988.

In an illuminating conversation, we explore what it feels like to see and hear stories of people criminalized for not disclosing their HIV status before sex. We cycle through the emotional toll the coverage can take and the complicated feelings it evokes. Robert says that people living with HIV are treated as pariahs and that Black people living with HIV face both HIV stigma and debilitating racism in how their stories are told.

Throughout our conversation he juxtaposes two key elements of his identity—his status as a person living with HIV and his identity as a Black person in Canada. As Robert points out, African, Caribbean and Black people living with HIV have pressing and unique concerns regarding the criminalization of HIV non-disclosure. To fully understand how deeply this issue impacts individuals and communities, we must first understand what it means to inhabit both of these spaces. To understand this moment in time, we must look at it in context.

In Canada, not disclosing your HIV status to a sex partner can, in some circumstances, be deemed a crime. Media stories of people prosecuted for not disclosing their status show Black men on trial in disproportionate numbers. What impact does this have on African, Caribbean and Black communities? Sané Dube investigates.

The first cases of people being charged for not disclosing their HIV status to sex partners date back to the late 1980s. Since 1989, more than 180 HIV-positive people have been prosecuted in Canada for not disclosing their status. A sharp rise in the number of cases, which began in 2004, has been accompanied by increasing severity in the type of criminal charges laid at the feet of people living with HIV.

Today, someone facing prosecution typically faces an aggravated sexual assault charge—a serious criminal charge with potentially grave consequences. If convicted, a person can be added to the sex-offenders registry and face a sentence of up to life in prison. In cases where the accused has immigrated to Canada, they may also face deportation.

In all of my conversations, the year 2012 pops up as a recurring focal point. That year the Supreme Court of Canada released decisions on two highly anticipated cases. The Court had been asked to clarify the conditions under which people living with HIV could face criminal prosecution for not disclosing their HIV status to sex partners. Legal obligations to disclose one’s status had already been in effect since the late ’80s, but in 2012 the court was asked to determine how using a condom or having a low viral load could impact criminal liability in cases of HIV non-disclosure.
By 2012 the global HIV epidemic was entering its third decade. Tremendous gains had been made in better understanding the biology of HIV transmission and advocates hoped that the highest court in Canada would seize this opportunity to integrate the latest scientific evidence on HIV transmission risks—showing that condoms and maintaining a low viral load significantly cut the risk—into legal processes. In a 1998 decision the Court had ruled that people living with HIV had a legal duty to disclose their status before having sex that might pose a “significant risk” of transmission. The court’s definition of “significant risk,” however, was vague and unclear, and advocates hoped that the 2012 ruling would bring greater clarity to the law.

Instead, the law became stricter. People living with HIV were now required to disclose their status before sex that posed a “realistic possibility” of HIV transmission. The problem was that sex posing a realistic possibility included situations where there is effectively zero risk. Critics called the decision a step back that diminished the rights of people living with HIV.

While the cases were being deliberated in the highest court in the land, they were also being dissected in the court of public opinion. One case involved a Black man accused of failing to disclose his HIV-positive status to several sex partners. Although HIV was never transmitted to any of his partners, he was charged with six counts of aggravated sexual assault.

By the time the Supreme Court issued its landmark ruling, dangerous and harmful ways of talking about HIV and, in particular, African, Caribbean and Black men living with HIV had become the norm. Some of the most discussed cases of that period involved Black men; the result was a disturbing fusion of Blackness and criminal deviance.

Looking back, people living with HIV and advocates describe popular coverage of criminalization cases during that era as uniformly poor, increasing stigma and undermining education and knowledge about the science of HIV. The coverage not only normalized language that framed people living with HIV as inherently deceptive and dangerous to the public, the disproportionate focus on people of African, Caribbean and Black descent, particularly straight Black men, told a singular, dangerous story.

The fusion of Black identity and negative stereotypes is not new. Indeed, it is something Black people and communities contend with daily. In another illuminating conversation, Shannon Ryan, the executive director of Black CAP (Black Coalition for AIDS Prevention), who has worked in HIV organizations for two decades, tells me, “Being Black in Canada means something. Systemically and institutionally, it means something—whether you stepped off a plane this morning or your family has been here since the 1700s. I try to remind the people I work with that our Blackness is something to celebrate and includes strength and solidarity. But in the world outside these doors, being Black can also include facing anti-Black racism, it means marginalization, it means oppression and vulnerability.” Contemporary narratives about the criminalization of Black people who don’t disclose their HIV status draw from and feed into these problematic and stifling conceptions.

Equally stifling is the criminalization that Black communities must contend with in the first place. Black people are vastly over-represented in Canada’s prisons. A 2015 report from the Office of the Correctional Investigator found that the federal incarceration rate for African, Caribbean and Black people in Canada is three times their representation rate in the general population.

“IT’S PUSHING PEOPLE AWAY INSTEAD OF ENCOURAGING PEOPLE WITH HIV TO COME FORWARD."

“The criminalization of HIV non-disclosure is another way our communities are being criminalized and torn apart,” says Ciann Wilson, an assistant professor at Wilfred Laurier University who has worked with African, Caribbean, Black and Indigenous communities responding to HIV. “HIV follows lines of existing inequity and the criminalization of people living with HIV further disenfranchises communities that are already dealing with structural racism.”

There’s an old adage that we understand the world around us by the stories we tell about it. A team of Ontario researchers analyzed 1,680 Canadian newspaper articles about HIV non-disclosure criminalization cases that were published between 1989 and 2015. They found that 62 percent of the stories focused on cases involving Black immigrant defendants, yet only 20 percent of the 181 people charged during the same period were African, Caribbean or Black men. The research team concluded that the media disproportionately focuses on cases involving Black people facing prosecution for non-disclosure.

“There’s no question about it: Straight Black men in particular are over-represented in the media coverage of these cases,” says sociologist Eric Mykhaliovskiy, one member of the research team. “If you take a closer look at the coverage, half of the 1,680 articles focused on four Black men facing prosecution. The fact that the coverage is so skewed toward those defendants really produces in the public imagination the idea that HIV non-disclosure is a crime of Black heterosexual men—when it’s not,” he says. “It’s a profound example of what is clearly a long history of over-representing Black people in crime stories in the media.”

The storytelling pattern Mykhaliovskiy references traces back to some of the first HIV non-disclosure cases involving African, Caribbean and Black men in Canada. Early media reports drew from racialized stereotypes about Black men, masculinity and gender. They conjured
images of hyper-sexualized Black men maliciously transmitting HIV to unsuspecting partners—usually white and female. News headlines frequently described defendants as “predators” while making reference to “potent” African strains of HIV.

The situation creates a paradox—one where ACB communities are over-represented among people living with HIV and where the public imagination creates strong links between blackness and HIV—yet interventions that cater specifically to ACB communities are limited. HIV in ACB communities is simultaneously hyper-visible and erased in the same breath.

ACCHO director Valérie Pierre-Pierre begins our conversation by reflecting on the coverage of HIV criminalization cases. “Even though high-profile cases don’t necessarily represent the majority of cases, the media covers those cases in ways that further demonize the accused. They elicit negative reactions toward people living with HIV, especially Black men.” She is referring to narratives that frame people living with HIV as maliciously transmitting the virus to unsuspecting partners. She and others in HIV service organizations argue that these portrayals have driven misinformation and stigma—which fuel fear and, in turn, create barriers to addressing HIV in ACB communities.

Black CAP executive director Shannon Ryan, reflecting on the aftermath of the Supreme Court rulings and the media coverage, says, “It does not help us do our work. It does not promote testing. It does not promote diagnosis. It does not promote disclosure. It does not reduce stigma. It diminishes our work.”

While proponents of the current law argue that it helps prevent HIV (that the fear of prosecution will make people living with HIV take precautions with their sex partners), many people living with HIV and many working in the field argue that the criminalization of non-disclosure and the discourses around it become marginalizing forces. In African, Caribbean and Black communities, this can have a particularly damaging and splintering effect.

Months after my first call with Robert Bardston and many conversations later, I have talked to people living with HIV, service providers, legal experts and researchers about the impact of HIV non-disclosure criminalization on African, Caribbean and Black communities and the stories we tell about it. To be sure, this is a difficult and divisive issue. Yet in the midst of it all, there are extraordinary individuals and groups resisting and challenging harmful narratives about these communities and criminalization.

They are claiming space and demanding this story be told a different way. They want the story to begin with an acknowledgment that structural violence and marginalizing narratives about African, Caribbean and Black communities drive increasing rates of HIV and, indeed, criminalization. Many also want to make it clear that the current system does not serve already-vulnerable communities.

Listening to their stories of resistance, I allow myself to start imagining and dreaming about a system that better serves our communities. +

Sané is a Zimbabwean transplant to Canada. She lives in Toronto.
Stigma Stings
Kath Webster speaks to 3 women who face stigma with courage and resilience.

Last January, my partner and I flew to Mexico for a vacation. On Day 1, out of the blue, I was stung by stigma. While swimming in the warm Pacific Ocean, I put my foot down, expecting to feel the soft sand, and instead stepped on a stingray, which spurred an excruciating sting and deep wound.

At the local clinic, I considered disclosing my HIV status, but this was a small Catholic town and I didn’t want to face people’s judgment or, worse, not be treated at all. So I decided against it. The doctor recommended stitches and wrote me a prescription for antibiotics. Worried they might interact with my HIV meds, I later resorted to Dr. Google (not recommended), which put my mind at ease.

My intense fear of stigma and discrimination caught me off guard and reminded me of the reality faced day to day by so many people with HIV. Because of my fear and my decision to not disclose, I did not receive optimal care that day. I was caught between a rock and a hard place: Both disclosing and not disclosing my HIV status came with its own set of risks.

I see my experience as relatively minor compared to what many people with HIV deal with every day. Especially for people who also face other forms of stigma—related to their race, gender, class, sexual orientation, being a newcomer, being a sex worker, using injection drugs, having a disability and other factors—the impacts can be serious.

Stigma is indeed one of the greatest barriers to a complete and satisfying life for people with HIV. In this era of effective HIV treatment, I have heard people with HIV say time and again that the stigma is worse than the disease itself.

Because misinformation and fear perpetuate stigma, I believe that by sharing our stories we can dispel myths and change attitudes. In the process, we can also build our individual and collective resilience to better address stigma.

The impacts of stigma and the ways we respond to it are as diverse as the people living with HIV. Here, three women share their stories and words of wisdom on how they have coped with it.

**WHAT IS HIV STIGMA?**
HIV stigma refers to the negative beliefs, feelings and attitudes that a person or society has about people living with HIV. Discrimination happens when people are treated unfairly due to stigma.

**WHAT ARE THE IMPACTS?**
A person who experiences stigma may feel judged, excluded and looked down upon. Stigma can take a toll on your self-esteem, cause depression, anxiety and social isolation, interfere with how well one adheres to their pill-taking schedule and deter people from accessing health services. Despite human rights laws that prohibit discrimination, it can also lead to people being denied housing, employment, healthcare and entry into a country. It can have serious impacts on a person’s mental and physical health. For some, stigma comes with a risk of violence.

The stress of disclosing your HIV status and fear of rejection can get in the way of romantic and sexual relationships. The Canadian HIV Women’s Sexual and Reproductive Health Cohort Study (CHIWOS) collected data from more than 1,400 diverse women with HIV in B.C., Ontario and Quebec over three years. Sixty-seven percent of participants agreed with the statement that “Most people with HIV are rejected when others find out.” The research suggests that despite good HIV treatment outcomes, many women living with HIV face challenges navigating healthy and satisfying sex lives.

When someone experiencing stigma comes to believe the negative messages and changes the way he or she views him- or herself, this is referred to as internalized stigma. Twenty-seven percent of the CHIWOS participants agreed with the statement “I am not as good as others because of HIV.”

Margarite Sanchez, who lives on B.C.’s SaltSpring Island and for years facilitated peer support groups for women, says that for many women internalized stigma is even more harmful than societal stigma. “Once you believe the stigma and internalize it, you can become your own worst enemy. I’m not saying there aren’t real dangers for women, but in some cases the isolation and separation are self-imposed because of perceived discrimination.”
Muluba Habanyama, 23
Mississauga, Ontario

Muluba was born HIV positive and lost both her parents when she was a teenager. She kept her HIV status a secret her whole life until 2014, when she disclosed in a YouTube video called “Feel No Shame.” Muluba has since spoken out about HIV at public forums and in the media. She is a CANFAR National Youth Ambassador and strong voice on three boards of directors for non-profit organizations.

Find your confident voice. When you hear negative messages, sometimes it’s better to just let them go.

I learned early on that I shouldn’t tell others about HIV, so I knew there was some sort of shame about it. As a kid, my mom always gave me my meds. They were a reminder of something I didn’t want to think about. Taking pills was also a real pain for sleepovers with friends.

When I was about 10, I discovered the Internet. That’s when I really started to see the negativity and awful thoughts that people have about HIV around the world. I thought, “Oh my gosh, are these things true?” Luckily I had my older sister to talk to and she advised me to ignore all the negative comments.

But it was challenging for me to have self-confidence and self-love and to express my feelings. It was hard to reach out for help and admit when I was feeling hurt and down. It got even more difficult when I started to believe what I saw in the media about HIV. I feel that stigma made me not like myself that much.

As I grew older I didn’t feel deserving of a relationship—it didn’t seem like an option for me. As a female, I already felt discrimination. Plus, I’m Black. HIV was yet another obstacle.

When I got really sick physically, at age 19, and had to deal with the mental and emotional side of HIV, it was a wakeup call. Maybe I had to nearly lose my life in order to appreciate it. I decided that to move forward I had to speak out. It took me a while to build up the self-love and self-confidence to disclose, but disclosing my status lifted a big weight off me. Once that secret burden was lifted I stopped stigmatizing myself. Now I feel no more shame. I’m so proud of how far I’ve come.

I wouldn’t have been able to disclose to the entire world on YouTube if I hadn’t seen HIV activists out there being strong. It means a lot to see people with HIV still fighting for what they believe in.

We are allies for each other. If all else fails, at least I will have their support! I appreciate all I have learned from different communities, like men who have sex with men and people who use injection drugs. These communities have been so welcoming. I feel like we’re all in this together.

I think that education is the key to fighting HIV stigma. The myths need to be dispelled and the general public needs to understand more.

Having a deep dark secret can be such a weight on your shoulders but I would never pressure people to disclose their status before they’re ready. I realize that most people don’t want to have HIV written on their face!

My advice to others is: Find your confident voice. When you hear negative messages, sometimes it’s better to just let them go. Be compassionate with yourself and others. Listen to your soul. Use your resources! Practice self-care, self-love, and don’t give a damn about other people’s opinions.

KIM, 51
Calgary, Alberta

When Kim lost her job in 2002, everything went downhill from there. Within a couple of years she lost her house and ended up living on the street. In 2011 Kim was diagnosed with HIV with a low CD4 count. She now lives in a one-bedroom apartment and volunteers in Calgary’s HIV community.

I first experienced HIV stigma right after testing positive. Although my boyfriend at the time tested negative, he beat me badly. He also told my father, sister and friends that I was HIV positive without my permission. I felt judged by most of them.

In 2016, I had to call an ambulance after tripping and sustaining a broken ankle and head injury. Because I was bleeding, I told the paramedics that I was HIV positive, at which point they became visibly uncomfortable. They started talking about me like I wasn’t there and they would barely touch me. Once I got to Emergency this treatment continued. The whole experience was traumatic.

I knew stigma before my diagnosis, too, as a result of living on the street. Some friends turned their back on me when I first started living on the street, and then I lost more friends after getting HIV. My self-esteem was nil. I always wore a ball cap and wanted to hide under a rock.

At this point I can’t imagine dating again, as I wouldn’t know when to tell someone that I’m HIV positive—would I tell them as soon as we started seeing each other or wait until getting intimate? Then there’s the risk of rejection, which would set me back. My mental health is deteriorating big time.

What has helped me the most has been getting involved with HIV organizations (like HIV Community Link and the Alberta Community Council on HIV’s Positive Voices.
or flight mode, and I chose to fight. I learned everything I could about the virus. I went to an All Nations Hope conference in Regina and decided that I would not die silently, like so many I knew. I couldn’t sit back and watch my people die. I feel the need to speak out and try to help fight stigma as much as possible. It’s been very healing for me to support others.

We need more voices, we need to be strong and teach our people. We have to band together as people living with HIV. HIV doesn’t walk in front of me causing me to stumble; HIV is not behind me as a burden; HIV walks beside me as my best friend would. I have to peacefully accept it. If my people can do the same and realize they’re not “bad” for getting HIV and they’re not throwaway Indians, it will hopefully change their mindset. First Nations are incredibly spiritual and this shift can be powerful.

As people with HIV we need to talk about our lives and be seen as humans, not just patients. We need more than medical teams and pills. Having mentors and peer navigators [people with lived experience who provide support to others with HIV] helps us feel connected and supported. We need the greater involvement of people with HIV/AIDS (GIPA), and more focus on mental health and spirituality, not just physical health. We need to remember the human in HIV.

If you want to talk about stigma, you’re talking to someone from the right province. We are truly in crisis mode in Saskatchewan—stigma is driving the high rates of HIV, especially in small communities. (In Saskatchewan, the number of people diagnosed with HIV in 2015 was more than double the national average: 14.4/100,000 compared to 5.8/100,000.)

I first encountered stigma at my first appointment with an HIV specialist. After telling the doctor that I had experimented with injection drugs but had never been addicted, he said that I would need to go on methadone and threatened that if I didn’t, he would admit me to the psych ward. Thankfully, my therapist was able to step in to vouch for me, convincing the doctor that I was not struggling with addictions and did not need methadone.

I lost many friends after disclosing my status. I have been spit on and called names like “diseased bitch” and worse. Because of stigma and discrimination I wasn’t even allowed to go to a sweat lodge. When I participated in a sacred Indigenous Sun Dance ceremony, people worried that they might get HIV from me via mosquitoes.

Stigma can be a huge problem in small towns or on reserves. In some First Nations communities, there’s not much confidentiality or privacy. If a relative works in the clinic, word can get out easily. This deters people from getting tested and seeking healthcare. That’s why we have so many late diagnoses in Saskatchewan.

I have even seen young pregnant women who are not diagnosed until the end of their term. The fear of having their HIV reported and the child taken into custody by child services once it’s born prevents some young women from getting tested or getting prenatal care. Imagine how hard that is for a young mom.

After my own diagnosis, I could have gone into fight mode or flight mode, and I chose to fight. I learned everything I could about the virus. I went to an All Nations Hope conference in Regina and decided that I would not die silently, like so many I knew. I couldn’t sit back and watch my people die. I feel the need to speak out and try to help fight stigma as much as possible. It’s been very healing for me to support others.

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As people with HIV we need to talk about our lives and be seen as humans, not just patients. We need more than medical teams and pills. Having mentors and peer navigators [people with lived experience who provide support to others with HIV] helps us feel connected and supported. We need the greater involvement of people with HIV/AIDS (GIPA), and more focus on mental health and spirituality, not just physical health. We need to remember the human in HIV.

If we as people living with HIV continue to share our stories—provided we feel safe enough to do so—we will surely challenge misinformation and generate more awareness and empathy, thereby chipping away at stigma.

After telling my stinger story to a friend, he was surprised that after more than 20 years living with HIV I still struggle with stigma. While treatment has advanced in leaps and bounds and HIV has become much more manageable, stigma remains rampant. Hopefully one day HIV will be seen as simply another health condition.

While we can’t control what happens to us, we do have some control over how we respond to it. History has shown that we are a resilient community. Let us respond to HIV stigma with the same passion and determination that we have shown throughout the history of the AIDS epidemic.

Kath Webster has been active in the HIV community since her diagnosis 22 years ago. Among other adventures, she helped bring the Positive Leadership Development Institute to B.C. Kath lives happily in East Vancouver.

**STIGMA INDEX**

The People Living with HIV Stigma Index charts trends in HIV-related stigma and discrimination in more than 90 countries. This peer-driven project aims to empower people living with HIV to speak out about stigma, and in doing so, create meaningful change. To learn about work being done in Canada and around the world, visit [www.stigmaindex.org](http://www.stigmaindex.org)
Managing Multiple Conditions

A doctor, a pharmacist and a person who juggles multiple conditions reflect on the challenges and offer their best advice.

INTERVIEWS BY SONY SALZMAN

ALICE TSENG
Pharmacist
Immunodeficiency Clinic,
Toronto General Hospital

Over the past five or 10 years, HIV medication regimens have become much simpler and managing HIV is now much easier. As people with HIV get older, many experience health problems other than HIV. People with HIV tend to develop some other illnesses sooner and at a higher rate than people without HIV.

One of the biggest challenges for people who are managing multiple conditions is taking many medications. The problems of polypharmacy have already been well established among seniors. These include the increased risk of drug interactions, side effects and hospitalization, as well as the increased challenges of medication adherence. HIV adds another layer of complexity to the already-difficult task of managing age-related conditions.

One of my biggest worries is “negative treatment bias”—a holdover from the early days of the AIDS epidemic. In those days, doctors were reluctant to treat an HIV-positive person’s other conditions because their life expectancy was so poor. You would think that because we’ve had effective therapies for more than 20 years now, that would no longer be an issue, but studies show that HIV-positive people are less likely than HIV-negative people to be treated for cancer and other treatable illnesses.

That negative treatment bias still exists for several reasons: lingering prejudice, doctors’ reluctance to prescribe new medications in addition to HIV drugs, and poor communication between specialists. But now we have a better understanding of how to safely prescribe multiple medications, so there’s no reason why a person with HIV shouldn’t be treated for other conditions as well.

Pharmacists have an important role to play for people managing multiple conditions. One key role is to identify potential drug interactions.

I always suggest that a person try to get all their prescriptions filled at one pharmacy because that becomes their touch point. A pharmacist can help you manage medications by creating blister packs, arranging home deliveries or modifying dosing schedules so you only have to take pills a few times per day. A pharmacist can also help you figure out what kind of drug coverage you’re eligible for.

My advice is to keep an up-to-date list of everything you’re taking—prescription and over-the-counter medications, vitamins, supplements and recreational drugs—as well as your medication history. Bring that list to all of your doctors’ appointments, especially those with new specialists.

I also encourage people to be their own advocates. I try to educate patients about the possibility of drug interactions so they can be prepared if a doctor prescribes a drug that could interact with something else they’re taking.

BILL DANIELS
Advocate for Aboriginal people and people living with HIV
Calgary

When I was diagnosed with HIV in 1996, I didn’t feel sick at all. I may have contracted it 10 years earlier, when I was at the height of my drug career and street involvement. But when I was diagnosed, I felt healthy and I was in good shape—all buffed up—so at first it was hard to comprehend that I had HIV, even though my CD4 count was 28.

I didn’t know where to turn for help. There were support groups in Calgary, but at the time they weren’t very accepting of Aboriginal people. The first time I went to a support group, everyone else there was male, white and gay. As a straight Aboriginal man, I thought, “Gee, what have I gotten myself into?” But I decided I wanted to learn about HIV so I kept...
going. The other members taught me a lot.

Eventually, I started volunteering at HIV Community Link and I became a board member of the National Aboriginal Council on HIV/AIDS.

Over the years I developed other health problems. I was diagnosed with diabetes 20 years ago. In 2003 I nearly drowned, likely because of low blood sugar. Some guys pulled me out of the pool and revived me. After that I was in intensive care for a week and a half, with breathing tubes down my throat. My kidneys shut down and the doctors said they might have been damaged. I also have spinal stenosis, which limits my mobility. I have heart disease and had to have bypass surgery following two heart attacks. And three years ago I started dialysis for kidney disease. So, yeah, you could say I manage multiple conditions.

It can be frustrating, but I’ve learned to cope as best I can. I learned how diabetes can affect you and how to manage it with my diet. I started testing my blood sugar levels. If it’s low, I know to have a snack before bed or drink some juice first thing in the morning. I’ve learned which foods spike my blood sugar (like pizza, pasta). I used to love desserts (I still do), but I know that I have to avoid them. I used to take metformin and a couple of other diabetes drugs, but now I’m off those. I control the diabetes pretty well with my diet.

I just turned 75 and had to step down from the board of the National Aboriginal Council on HIV/AIDS. Sometimes I feel depressed. I get tired of treatments, ordering supplies and testing my blood sugar, and I’m sick of dialysis. But I’ve always had an attitude of “just do it.” I have to live with these conditions every day, so I have to do what I need to do to stay healthy. There are days when I don’t want to get up but I tell myself, “You gotta get up. You’ve got things to do.”

You have to get a doctor who’s knowledgeable. And you have to try different things. Before I went on dialysis, I tried yoga, working out, even meditation. I find that meditation lessens my pain.

I’m not a practicing Buddhist but I read a lot about Buddhism because I like the philosophy and psychology behind it. I’m Métis and I find that a lot of Aboriginal teachings are similar to Buddhism.

I’m lucky because I also have a great support system. My wife has been with me for 46 years, and she does so much for me. My son and three daughters check in on me regularly. I also have a couple of friends who help out. One of them has a car so when there’s an emergency, he’s there to help out with a drive.

I still attend lunch meetings at HIV Community Link regularly. Anyone living with HIV in Calgary should try to go to HIV Community Link. They have great supports and resources for people.

**DR. MARIANNE HARRIS**

Clinical Research Advisor
AIDS Research Program,
St. Paul’s Hospital/UBC
Vancouver

It was only after the first highly active antiretrovirals came out in 1996 that the medical community started to view HIV as a chronic condition rather than an acute disease. With effective medication, HIV was no longer a death sentence. But it was more than a decade before we really understood the impact that effective HIV medications would have on people’s lifespan.

As people with HIV aged, many started to acquire chronic conditions. Some of the more common conditions include cardiovascular disease, lung diseases such as bronchitis or emphysema, and certain cancers, as well as depression and anxiety.

People can start to feel that their medical conditions are taking over their life, which is never a good thing. Managing multiple conditions can be especially challenging for people who have already spent years taking HIV medications and using the medical system. People can get pill fatigue, which, in turn, can result in missed doses. They also experience doctor fatigue, which is when you get tired of all the tests and medical appointments. In addition, because healthcare specialists don’t always communicate with one another, patients might get conflicting advice, which can be confusing.

But there are many things you can do to cope with these challenges. First and foremost, I recommend that each person spend time thinking about their own priorities and play an active role in their care. For example, someone who works from home might not mind having to make frequent trips to the bathroom, but people who have to travel for work can’t imagine having to take a pill that gives them diarrhea. Every person has different preferences and priorities, and if your doctor knows about yours, it can help them reassess your treatment plan.

Find a doctor you can talk openly and honestly with. Your doctor might even be able to suggest a lifestyle change, such as diet or exercise, which is always better than having to take more medications.

Getting support from family members, friends, support groups and peer navigators can also be hugely helpful.

Sony Salzman is a freelance writer based in Brooklyn, New York. Her work has been published in The Boston Globe, Al Jazeera America and The Body.
The Best of Both Worlds

Tradition meets innovation in the work of William Flett.

By Darien Taylor

One of William Flett’s earliest childhood memories is of the plane he was travelling on touching down on the tarmac in Haida Gwaii one dark, rainy night. He was five years old. Though William and his parents lived on the islands of the Haida people, situated off the north coast of B.C., for only a year before returning to Vancouver, its culture and rich artistic traditions had a lasting impact on William’s artistic expression. The Haida reverence for the natural world and their depictions of spiritual encounters with local wildlife have inspired William’s pictures of bald eagles, bears and orca whales.

Since his HIV diagnosis nine years ago, at age 19, William has been drawn increasingly to the art and culture of his ancestors. “Traditional Native art has always been important to me,” William says. “But I didn’t have the opportunity to learn about the significance of the animal crests in Native culture [depictions of animals and mythical creatures that decorate totem poles, furniture and other objects]...”

“Because I grew up learning about many native cultures, I feel it’s important to reflect that unity.”
and make my own designs until after my diagnosis.”

Although several of his animal crests are Haida, he doesn’t focus solely on animals associated with the Haida people. “I’d like to do a turtle and a wolf crest, which are more East Coast animals. Or a thunderbird, which is featured more in native art from the Seattle area,” William says. “I didn’t grow up in an exclusively Haida environment. Because I grew up learning about many native cultures, I feel it’s important to reflect that unity of all native peoples when making new yet traditional designs.”

Animal crests convey traditional Aboriginal stories about creation and the natural and the spiritual worlds. William’s first crest, an eagle, came from an art assignment to create a self-portrait. “My family crest is the Double-Headed Eagle, and my native name translated is Big Eagle. I enjoyed the significance of that connection,” he says. The work pays homage to Haida carver, printmaker and painter Robert Davidson by closely following the style of Davidson’s representation of this mythic animal.

William has used his more recent animal crests—mostly digital prints but also some acrylic paintings—to grow as an artist and offer something new. They tend to focus on an obscure part of an animal story not traditionally represented. For example, Haida images from the story of Raven bringing light to the world traditionally depict Raven with the light in his beak, carrying it to the moon, the sun and the stars. But William’s crest depicts an earlier part of the story, one not often visually referenced, where the Raven sits atop a tree, disguising himself as a pine needle.

Or sometimes William chooses to depict an animal that is not central to the story. “There are not many Haida stories where Frog is the focus,” he explains. “But in many of the stories of creation, Frog communicates with the Creator. I’m interested in showing Frog’s connection to the spirit world, to the moon, the nighttime, the stars, the ethereal realm.”

His Killer Whale is perhaps the crest that William is most proud of: “It’s the one that I created from scratch with very little reference to earlier Aboriginal artists. This one is the most me.”

William’s mother and grandmother both influenced his development as an artist. As a young adult, William’s mother, Norma Abrahams, seriously pursued argillite carving. His grandmother, Peggy Shannon, a prominent member of the local Indigenous community and a counsellor at Capilano University in North Vancouver, did bead work. As arthritis became an issue for her, she did more trading with other Indigenous crafters who specialized in abalone and other shell buttons used for making traditional Haida button blankets. “Wherever I went with her, like to the Native Friendship Centre on crafting or potlach nights, people recognized her,” William recalls.

He cites a number of Haida artists whom his grandmother counts among her friends as major influences on his art, including Robert Davidson, fashion designer Dorothy Grant, sculptor Bill Reid, and jeweller and television host Tamara Rain Bull. “I’ve studied their work, mimicked their styles and learned from them,” he says, “especially how to mix the traditional and the modern.”

But William shakes off the suggestion that his art and well-being as a person living with HIV are closely connected. “The drive to express myself through my art could be an aspect of self-care and self-reflection,” he says, “but I don’t feel art is as important in
William’s involvement with YouthCO helped to stabilize him after finding out he was HIV positive during his first year of study at VanArts. “I was out of classes for two weeks with what I realize now was seroconversion illness. At the time, I thought it was just a bad flu.”

Unfortunately, the seroconversion illness that William experienced played havoc with his sleep habits. He couldn’t get out of bed in time for classes. Coupled with the bout of depression he experienced post-diagnosis, William ended up dropping out of his program at VanArts but says he might return to visual effects and film at some point in the future.

For William, the worst part of living with HIV is the stigma. On Halloween day, a few months after he had started taking antiretroviral medications, his mother found one of his pill bottles and discovered online what it was prescribed for. All hell broke loose in the house where William lives with his mother, other family members and “random friends.” William received an urgent phone call from his father, telling him that his mother now knew about his diagnosis and that the news was spreading like wildfire. “It was a scary Halloween in a way I hadn’t expected,” William laughs ruefully.

HIV may have diverted William from his chosen career path but it has opened up new roads for him to pursue. He has become a sex-positive community educator who draws on his own experiences living with HIV. And he is an artist with his foot in two worlds—the vibrant world of what has been called a “renaissance” in Haida arts and crafts, and the modern technologic world of film and visual effects. “I have no idea where this is all going, but the journey is interesting.”

Darien Taylor is CATIE’s former Director of Program Delivery. She co-founded Voices of Positive Women, to empower and support women living with HIV, and is a recipient of the Queen Elizabeth II Diamond Jubilee Medal. Darien has been living with HIV for more than 20 years.
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