Christian Hui takes on stigma

Grappling with addictions
Pozitively sexy
Disclosing to kids
Breaking free from hep C

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EDITOR’S LETTER

Most of us have either struggled with an addiction of some kind or know someone who has. The object of desire might be alcohol, drugs, sex, gambling, the Internet, you name it—compulsions come in all shapes and sizes. And they have a long history of crossing paths with HIV.

Certainly, being drunk or high can increase the chances of HIV transmission. And an addiction can make it a whole lot harder to take your HIV meds every day. But an addiction can also be a coping strategy—a way of relieving stress, soothing pain, feeling in control, connecting or disconnecting.

As HIV activist Christian Hui, whose handsome face graces the cover of this issue, explains in his profile, using substances was for him a way to deal with his HIV diagnosis and not feeling accepted by society. Today, while he energetically counters stigma and builds coalitions for people with HIV, he acknowledges that recovery is an ongoing and lifelong endeavor.

So what’s the key to moving through it to a better place? Some would say, understanding what fuels one’s addiction. In Ask the Experts, neuroscientist Marc Lewis challenges the dominant view of addiction as a disease; Angela Thomson shares her personal story and reflects on her work as a peer navigator; and psychoanalyst Marco Posadas makes the case that we need to stop pathologizing people’s substance use and address the root causes.

While the failed “war on drugs” has made it clear that demonizing and criminalizing drug users is both inhumane and ineffective, programs that adopt a harm reduction approach continue to treat people who use drugs with respect and without stigma. In From the Front Lines we shine a light on programs that do just that.

Also in this issue: In “Let’s Talk About Sex,” we explore how treatment as prevention and PrEP affect people’s sex lives. We take an in-depth look at positive parenting. And in Art Posi+ive we speak to the talented Margarite Sanchez, for whom art and life form a seamless whole.

We hope you enjoy this issue of the magazine! As always, we want to hear what you think, so please drop me a line at dkoenig@catie.ca

—Debbie Koenig
Peer support and mutual aid have always played a role for people who use drugs—from reducing the risks of drug use and preventing overdoses to sharing critical information. In the 1980s, in the face of the AIDS crisis, harm reduction took to the stage as an approach to reducing the risk of HIV transmission through injection drug use.

Harm reduction refers to policies, programs and approaches that aim to minimize the potential harms of drug use. It recognizes that doing recreational and street drugs can be an individual choice and that some people may be unable or uninterested in stopping. Harm reduction is about providing people with the tools they need to survive, be as healthy as possible and live with dignity.

Many harm reduction advocates are themselves drug users. The slogan Nothing about us without us insists that people who use drugs be involved in every level of harm reduction initiatives—from setting priorities to deciding where resources go to doing the work itself. In this spirit, we take a look at five initiatives across the country that offer various kinds of support to people who use drugs.

**Natural Helpers**

**Peer outreach in Cape Breton**

While we’ve long known that sharing needles can spread blood-borne infections like HIV and hepatitis C, people who inject drugs don’t always have easy access to new needles, not to mention healthcare and information on safer using. This is where natural helpers come in.

Research has shown that one of the best ways to serve marginalized communities like people who use injection drugs is to connect them with “natural helpers”—people with a deep personal understanding of that community to whom others naturally turn when they need support. The Natural Helpers of the AIDS Coalition of Cape Breton’s needle exchange (SANE) work to reach as many injection drug users as possible. They either have used injection drugs themselves or are family members and friends of people who do.

Natural Helpers work to prevent HIV and hep C by providing people who use drugs with new injection equipment, biohazard containers for the safe disposal of used needles, and information on how to use safely. They extend SANE’s reach by distributing equipment in rural and remote regions that may only be visited by an outreach van once a month, or not at all.

Natural Helpers also report back to SANE about new or bad drugs on the market and ways that harm reduction information is being used on the street. This helps the program remain relevant to the people who use it.

aidscoalitionofcapebreton.ca / 902.539.5556

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**TORONTOVIBE**

**Promoting safer partying**

Torontovibe.com, hosted by the AIDS Committee of Toronto, provides the gay/bi/queer community with information about safer drug use. The website was launched to respond to substance use concerns such as the risk of overdose and how street drugs can interact with HIV drugs.

The site provides visitors with facts about drugs—from alcohol and pot to cocaine, crystal meth, E and K—so that they can make informed decisions about their drug use and reduce the risks. For each drug, there is information about the risks, how it can affect sex, and how HIV meds and other drugs can interact with it.

Torontovibe.com boasts a few unique features, such as a place to report and read up on bad drugs in the community so that people can avoid them. The site also lists known interactions between recreational drugs and HIV meds. Clearly there is a need for this kind of information, as last year alone 36,970 people visited the site.

Torontovibe.com
Blood Tribe Naloxone Program
Preventing overdose deaths

In recent years the Blood Tribe, or Kainai First Nation, has faced a wave of overdoses. At times, hospitals were seeing three overdoses a day. The cause? The powerful opiate/painkiller fentanyl, which is being used in more and more communities across Canada. This surge in overdose deaths led the Blood Tribe, in southern Alberta’s Blood Reserve, to declare a state of emergency.

In response to the crisis, in 2015 the Blood Tribe partnered with the HIV community organization ARCHES and the local health authority to distribute naloxone kits and train healthcare workers and community members to administer it. Naloxone is a medication, usually given by injection, which stops people from overdosing from opiates long enough to get them to a hospital, buying precious time.

The Blood Tribe program was the first on-reserve naloxone distribution program in Canada. Workers inform and educate people about fentanyl and related risks. They work to expand supports for people dealing with opiate dependencies. This includes improving access to Suboxone, a prescribed substitution therapy widely recognized for reducing HIV and hepatitis C transmission.

Thanks to the leadership of the Blood Tribe, and Drs. Esther Tailfeathers and Susan Christenson, who dispense the take-home naloxone, a number of lives have already been saved.

bloodtribe.org / 403.308.0760

CACTUS MONTREAL’S PIPE DISTRIBUTION
Reducing the risks of smoking crystal meth

In the past few years, the staff of Cactus Montreal has seen crystal meth use soar among people who use its services. The community centre runs a fixed site to distribute equipment for injecting drugs and using crack.

Crystal methamphetamine—meth, Tina, T—is a stimulant that can be sniffed, smoked or injected. As with many drugs, the sharing of pipes and injection drug equipment carries a risk of transmitting HIV and hep C. Montreal has seen an increase in people injecting crystal meth, as opposed to inhaling or snuffing it. (As people’s tolerance to the drug increases with regular use, many start injecting it because this produces a stronger and more immediate high.) Many people who are new to injection drug use and aren’t tapped into harm reduction programs don’t have access to the same prevention information and are more likely to share or reuse their pipes and needles.

To respond to the growing number of people using meth, Cactus staff started distributing crystal meth pipes. This allows them to disseminate information about how to prevent hep C while providing people with new equipment. Plus, if people who smoke switch to injecting, they will have the know-how and material needed to do so more safely.

Cactus charges $5 per pipe. They hope to eventually be able to offer them for free. The Fixed Site is open seven days and nights a week.

cactusmontreal.org / 514.847.0067

Eastside Illicit Drinkers Group for Education (EIDGE)
Harm reduction for drinkers

In Vancouver’s Downtown Eastside, Rob Morgan and John Skulsh were seeing their peers and friends dying at an alarming rate, but it wasn’t from the causes people usually associate with the neighbourhood. These deaths were related to illicit alcohol consumption and a lack of services for people who drink. Illicit alcohol is alcohol not intended for human consumption (such as mouthwash and hand sanitizer), homemade alcohol (like moonshine) and alcohol consumed in ways considered criminal (for example, drinking in public). It is cheaper and often easier to procure.

The deaths that Morgan and Skulsh were seeing were sometimes due to the effects of illicit alcohol on the body but were often not directly alcohol-related—pneumonia and exposure to cold from sleeping on the street, sometimes the result of cutbacks to the number of shelter beds.

Zero tolerance policies among social services and many shelters for people under the influence also play a role.

With the support of the Vancouver Area Network of Drug Users (VANDU), Morgan, Skulsh and other drinkers got together to start EIDGE. The group meets once a week to build awareness and to push hospitals, police and health services to change policies. A main focus of EIDGE is the creation of a non-residential managed alcohol program (MAP), a place where alcohol users can go to drink safely and access services, such as counselling and referrals, without fearing altercations with police. MAPs are recognized harm reduction tools that exist in cities across Canada. “If we had a place where members could drink safely,” Morgan says, “we’d be able to prevent a lot of these deaths.”

vandu.org/groups
We asked 4 poz parents:
How do you talk to your kids about HIV?

Interviews by RonniLyn Pustil, Alexandra Murphy and Debbie Koenig

MARISOL DESBIENS, 38
Mother of 2
Diagnosed with HIV: 2004
Research associate at Women’s College Hospital and
McMaster University
Toronto

When I was diagnosed, my daughters were three and four years old. I first told them that I was HIV positive when they were 11 and 12 because their father was hospitalized and the whole family showed up—they all knew about his HIV status but the girls didn’t. The social worker was concerned that the girls would find out from their cousins.

Once my husband’s health had improved, I decided to tell my daughters about mom and dad being HIV positive. At first they were shocked, confused, anxious and sad. They didn’t know what HIV was. Their first question was: Are you going to die from HIV? I told them, not as long as I take

“I feel that my job is to help my daughters fully understand HIV so that they can protect themselves.”

 Sadly, Marisol Desbiens died suddenly on May 18th, 2016. Marisol was very involved in doing community work and was a dedicated and trusted community facilitator for CATIE’s Hepatitis C Ethnocultural Project. We wanted to share her story and insights with her family, friends, colleagues and other Positive Side readers. We extend our condolences to her daughters and to the many people whose lives she touched.
my medications every day, see the doctor regularly and take care of myself.

I asked the Teresa Group [an organization in Toronto that serves families affected by HIV] to help me talk to my girls because I was concerned about their emotional and mental health. A family support worker talked to the girls in a way that they could understand. They had weekly counseling sessions until the girls were more comfortable and knowledgeable about HIV. The support worker answered their questions and helped them deal with their emotions.

When the girls were little I used to tell them that I needed vitamins. As they grew older, they noticed that the medications were not vitamins, but they never confronted me about it. Now they know and they are not worried or scared. When I disclosed to them, they were happy that I trusted them enough to tell them the truth. They said if I had kept it a secret, they would have been disappointed and angry with me because that would have meant that I didn’t trust them. It’s better for them to know because they can support me, love me and care for me, and that’s very important to them.

I’m now more confident when it comes to educating my daughters about HIV and we continue to have conversations about it. When it comes to sexual health, I feel that my job is to help my daughters fully understand HIV so that they can protect themselves from high-risk behaviours, such as unsafe sex and unsafe alcohol or drug use. Sometimes we talk about what they learn at school, for example, that people can get HIV through kissing. I have to educate them and tell them that you can’t get HIV that way.

I’m happy to be free from worry that the girls might find out my secret. They have a right to know the truth, and, as a result, our relationship is stronger because of the level of trust and comfort. They are very supportive and encouraging of me, and I have supports in place for them in case they feel down, sad or anxious. They know not to disclose my status because I don’t want anybody to discriminate against them, especially at school.

**DAVE, 39**
Father of 2
Diagnosed with HIV: 2011
Project coordinator with a national Indigenous organization
Halifax

I didn’t become HIV positive until after my divorce when I became openly gay. It was my first long-term relationship with another man. My son and daughter were nine and 11 at the time; they first learned about my diagnosis when they were 10 and 12.

I knew it was something they needed to know, I didn’t want to keep anything from them. However, I was really scared to tell them, as they were already dealing with so much (the separation of their parents and the everyday stresses of figuring out who they are as people). I didn’t want them to worry about me. They knew a bit about HIV because their uncle is also living with the disease.

My ex-wife and I are not on good terms and she does not allow me to see the children on account of my being gay and living with HIV, so I had to tell them on the phone. This was very difficult to do. It broke my heart because I really wanted to be with them to hug them and let them know I was going to be OK.

Disclosure can be difficult on so many levels. It’s about much more than just saying, “I have HIV.” You have to look at the whole picture. Trying to explain why mommy and daddy are not together was hard in itself and not having support from my ex was difficult too. I think it would have been much easier to disclose my HIV status if that was the only thing that needed an explanation. But with children you often have the “why” and “how” questions and the fear that they might not accept your answers and could reject you.

My kids’ reaction was mild. They really didn’t have a reaction as far as I could tell but at that age it’s hard to understand their feelings. They didn’t have many questions except “are you going to die?” My heart got heavy but I felt I had to stay composed. I didn’t want my feelings to scare them any more than I imagined they already were. I explained that I had a good doctor who was taking very good care of daddy.

My children have always been very compassionate toward others and I wanted them to understand HIV. It is only because I became involved with HIV education and peer mentoring after my diagnosis that I was able to even think about having that discussion with my children.

**FLO RANVILLE, 48**
Mother of 7
Diagnosed with HIV: 2000
Peer mentor and interviewer, BC Centre for Excellence in HIV/AIDS
Vancouver

When I found out I was HIV positive, my six children were in foster care. (I gave birth to my seventh child a year later.) I had struggled with drug and alcohol addictions for years, which led to them being in and out of foster care.
I have started to explain to her how it can be transmitted. When she’s older I will tell her that it can also be passed during sex. Right now I think she’s a bit young for that.

One day I will tell all three of them that I’m HIV positive. How will they react? To be honest, I have no idea. The conversation will most likely lead to questions, and I want my children to know that they can ask me them down the road. I think the important thing will be for me to be available to answer their questions as clearly as possible and to stand by them, so that...

I used a flip chart to show her what HIV is. I taught her about antiretrovirals and how important it is for me to take them. When I asked her if she understood or had any questions, she said, just take your meds mom.

What helped my children move from fear and worry to acceptance? One day my eldest daughter came with me to an appointment with my HIV specialist Dr. Julio Montaner. That was huge. It helped put her at ease. She saw that the people at the immunodeficiency clinic weren’t a bunch of dying people. She heard Dr. Montaner say that I was doing well and that if I continued to take my meds, I would be fine. She was so impressed with him. That helped her to come to acceptance.

When my youngest daughter was born HIV negative, it showed my other kids that the medicines work.

I also had great support from AIDS Vancouver for 10 years—they were kind and empathetic and helped support my family. The other thing that made a big difference was Camp Moomba, where my kids got to meet other families affected by HIV.

Today we are happy. We don’t talk about my health—except I share good news that mom has been doing well. We talk about their lives. They are now 14, 17, 19, 21, 22, 23 and 26. And I have two grandchildren.

LAETITIA, 37
Mother of 3
Diagnosed with HIV: 2004
Montreal

I come from Burundi, in central-east Africa. When I was diagnosed with HIV, I was 25 years old and my three children weren’t yet born. Now my kids are one, five and nine years old. In my opinion, they are too young to understand what being HIV positive means, but I’m starting to prepare the oldest one for having this conversation. I have explained to her that I am a bit sick (without naming HIV) and that I need to take medication every day. I reassure her that the illness isn’t anything serious or anything to be afraid of, and that I will not die from it.

The Ministry of Children and Family Development told me that I needed to tell my eldest daughter, who was almost 12 years old, about my HIV status. I had to disclose to her in a boardroom along with her foster mom. My daughter looked so sad and heartbroken and angry with me.

A few months later, the foster home closed and she came back to live with me. At first when she was angry with me or didn’t get her way, she would call me names and tell me to die already. I managed to survive that time and have regular visits with my other five children.

I told my two boys when they were 13 and 14 because they wanted to know why I had to take so many pills. They were pretty quiet about the news. I tried to reassure them by saying that as long as I stay clean and sober and take my meds every day, I will live as long as anyone else. They would then remind me to take them.

I disclosed to my two youngest children, now 14 and 17, just two years ago. The older one stopped associating with me for about a year. She would only come over for birthdays but now she comes over to visit and joins us for family get-togethers. With my youngest their journey to understanding and acceptance goes smoothly. I do not want to rush the process. And we will seek help if need be.

I expect that the conversation will go well. I have an amazing support system in place. I have a wonderful family as well as other resources and supports, including a great social worker and the organizations I’m in contact with that provide information and assistance to people living with HIV.

After telling them, I think I will feel a big sense of relief.
“Never, no time, not ever.” That was Mary’s reaction when asked if she had considered telling her three children she is living with HIV. Mary and her oldest daughter, Lydia, emigrated from Sub-Saharan Africa to Canada when Lydia was an infant. Learning that she was HIV positive in the early 2000s was an extremely difficult time in Mary’s life, but she was enormously relieved to discover that her baby had not contracted the virus. After settling in Canada, Mary got married and had two more children. Her HIV was well controlled and she was active in her family life and in her community.

When Mary first came to The Teresa Group [an organization that serves families affected by HIV], the only person she had told about her HIV was her husband. But Lydia, then 14, had started asking Mary about her medications—what were they and why was she taking them?—and Mary

Show and Tell

How to disclose your HIV status to your kids.

BY NICCI STEIN
needed some help. The family support coordinator encouraged Mary to bring her daughter in to assess how ready they both were for a disclosure conversation.

When Lydia subsequently spoke to a counsellor, she asked, “Why does my mother lie to me? She says she’s fine but she takes pills every day and she won’t tell me why. When I ask her, she avoids the question. Is she sick? Is she going to die?” The girl’s imagination was running wild.

Parents are often reluctant to disclose their HIV status to their children and many say that they intend to never tell. But as kids grow older, they can often sense that something is up, and start to wonder what’s going on.

**What concerns parents?**

At first Mary said her children were too young—to understand what HIV is, to keep it a secret and to know about HIV. She also never wanted to get into with her kids, never to tell. But as kids grow older, they can often sense that something is up, and she didn’t want to disrupt their lives.

After a longer conversation with a counsellor, Mary began to voice some of her deeper and more troubling fears. She also didn’t want her children to know about something that had filled her with pain, shame and guilt. She had contracted HIV in a context of violence and trauma and had done a lot of work to come to terms with that. She didn’t want to dig it all up and tell her children about it.

Like most parents, her instinct was to protect her child. She didn’t want to see the look on their faces as she passed her “burden” on to them. She was also afraid that they would judge her. She feared that they would look at her and think about her differently and she didn’t know how she would deal with that.

**What are the experiences of children?**

By the time she was 14, Lydia had become angry and confused. She knew her mother was taking medications for something but whenever she asked why, she felt brushed aside or her mother changed the subject. Lydia grew resentful—and scared. “It must be something really bad or she’d tell me,” Lydia speculated to the counsellor. “Doesn’t she trust me? Maybe she has cancer like my friend’s mom. Maybe she’s going to die. I can’t think about her dying, I can’t.”

This kind of situation is not uncommon. Although it might seem easier to not talk about HIV with your children, research shows that generally there are some definite benefits to disclosing for both parents and kids—provided that the way children are told is planned and age-appropriate and that the person disclosing is well supported and feels confident enough to deal with whatever issues and questions might emerge.

Several studies have suggested that disclosure can benefit an HIV-positive parent’s mental health, adherence to HIV medications and family relationships. Research has also shown that disclosure can improve a child’s emotional and social well-being. Children report feeling better prepared for the future, more involved in family decision-making and closer to their parents. While they might initially be worried, sad, shocked or angry, these feelings tend to diminish over time and younger children, in particular, seem to experience no significant long-term problems as a result of learning of their parent’s HIV status. HIV tends to become normalized in their lives, especially if the parent’s health remains good. The literature suggests that few parents regret disclosing, and that doing so often leads to a stronger parent-child relationship.

**Overcoming the fear**

There is no right age for a parent to tell a child about their HIV status. Every child is unique and reacts differently. There are various ways of disclosing that are appropriate to the child’s age, including partial telling (for example, saying you have a health condition without naming HIV specifically), and later disclosing more fully.

Here are some things to consider before disclosing to children:

- **Talk to someone who can help.** It might be another parent living with HIV, a counsellor, healthcare professional or support person who works at an HIV organization.
- **Think carefully about when and how you want to tell your children.** Do you want to tell only the oldest for now or all of them together? Consider their ages and maturity levels. Together with your support person, take time to plan the conversation carefully—who and how to tell, when to tell and what to say.
- **Practice what you will say.** Rehearse it with your support person. Practice it out loud on your own. Try to anticipate the questions your kids might have and how you will answer them.
- **Be prepared for your kids to hear you, shrug it off and move on.** Sometimes kids do that. It could be anticlimactic! Or they might listen and need time to digest the news.
- **Who will support you afterwards?** Make sure there is someone supportive you can talk to and debrief with after you tell your kids for the first time.
If and when you decide to tell:

- **Try to be as relaxed and present as possible when you talk to your child(ren).** Staying calm and connected will help set the tone of the conversation. Kids can be quick to pick up on facial expressions and body language and may take their cues from you.

- **Choose a time and place when you won’t be interrupted.** You might want to turn off your phone and make sure there is ample time for questions and conversation.

- **Stay open.** Listen to their questions and insights. Try to understand how they might be feeling. Ask your children to repeat back to you what you’ve just said. This will allow you to see what they have internalized and how they have understood it.

- **If confidentiality is an issue, talk about why you want to keep this private and not tell everyone.** Tell your kids how you’d like them to handle the potential telling of others. Explain who knows, who doesn’t and who you’re OK with knowing.

- **Remember that your child(ren) will need someone to talk to about this other than you.** Maybe it’s an older sibling, a peer who is also affected by HIV, a counsellor, teacher, healthcare professional—someone the child trusts who can support them.

- **Check in regularly with your kids.** Ask them how they’re feeling and if they have any questions. But also remember that it is OK to just get on with life and not talk about HIV all the time, if that’s where they’re at.

- **Keep them informed about your health and your doctors’ visits** to allay any worries or fears they may have.

- **Keep in mind that disclosure is an ongoing process,** not a single event. Commit to an ongoing open and honest conversation with them.

Nicci Stein is the executive director of The Teresa Group, a community-based organization that advances the dignity and well-being of families affected by HIV in Ontario.

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Tools for Telling

Videos about kids and youth living with or affected by HIV can be inspiring and useful tools for both parents and children. Check out these YouTube videos:

- Ashley Murphy at a WeDay gathering in Ottawa
- “Feel No Shame”, Muluba Habanyama on being born with HIV and going public

These booklets offer additional info about disclosing to children:

- *How Do I Tell My Kids? A Disclosure Booklet About HIV and AIDS in the Family,* available through The Teresa Group at info@teresagroup.ca or 416.596.7703
- *HIV Disclosure: Figuring Out How to Tell Children & Family,* available through the CATIE Ordering Centre at orders.catie.ca or 1.800.263.1638

An HIV organization can provide a supportive environment that normalizes living with HIV. Friends and peers can help too if they are OK about being out and identified to your children.
Back from the Brink

Shazia Islam sits down with HIV activist Christian Hui to learn about how he’s fighting stigma so that others don’t have to go through what he did.

PHOTOGRAPH BY MICHELLE GIBSON

The scene opens with seven men sitting on chairs arranged in a circle. An awkward silence permeates the room until a counselor among them asks one of them to begin. Lucas ponders what his family might think if they ever find out that he’s hooked on crystal meth. Chen is next. He lists all that he has lost: his house, his job, his partner. Then Jeremy talks about his desire for love and acceptance as Alex, the main character, gives him a knowing look.

Empty Nest is a short film, written by Vince Ha and Mezart Daulet, based on the life of HIV activist Christian Hui. The title refers to the sense of emptiness that sometimes accompanies addiction, but the film brings to light how the right supports helped Christian break away from that emptiness.

It was a late Saturday afternoon when Christian, a mug of French-pressed coffee in hand, sat down with me to talk about what matters most to him. There was no sugar-coating the issues as he graciously took me on a journey through some of his life-altering struggles and triumphs as a gay Asian man living with HIV.

Christian’s depth of knowledge and experience with the HIV movement could potentially be intimidating but he has a way of putting you at ease when you meet and talk to him in person. He is warm. He is humble when talking about his achievements, but then assumes a resolute tone when the discussion shifts to the work that needs to be done to end stigma against the communities he so passionately advocates for.

Christian’s achievements are many: He recently spearheaded a national organization for people living with HIV and hepatitis C (the Canadian Positive People Network (CPPN), see page 15) and coordinated the launch of Ontario Positive Asians (OPA+), the first network for Asians living with HIV in Ontario. He coordinates community engagement at Asian Community AIDS Services (ACAS) and does peer work to promote the sexual health of newcomers with HIV through the Committee for Accessible AIDS Treatment (CAAT).

While doing all that and more, he also just completed a bachelor of social work at Ryerson University, where in 2015 he received the President’s Award for Community Engagement and more recently a full scholarship to pursue his master of social work. No small feat for someone who had to rebuild his life in the aftermath of not only an HIV diagnosis but also considerable bullying and rejection throughout much of his childhood and youth, followed by an addiction to crystal meth and, in 2010, a hepatitis C diagnosis.

Born in 1978, Christian grew up in Hong Kong before moving with his family to Seattle when he was 12. A shy and socially awkward kid who knew he was attracted to people of the same gender, he had already endured years of bullying by then. In Seattle, he continued to be ostracized for having a foreign accent and wearing “different” clothes.

But he was bold and brave enough to become a sex educator in his teens, giving talks to his peers. He points out that it was kind of ironic that he would go around to classrooms telling students how to put on a condom when he didn’t know how to put one on himself. And he pushed himself to high academic standards at school. But he recalls being shunned for being who he was: a young gay Asian man.

Life was to get tougher still. After his father lost his business in Hong Kong and could no longer afford to pay for Christian to complete his business degree at an Ivy League school, in 1999 the family relocated to Toronto. At first Christian had no friends, no money and difficulty landing a job...
“The use of substances was how I learned to cope with my HIV status and not being accepted by society.”

because, like so many newcomers, he lacked “Canadian experience.”

To meet men, Christian went online and to clubs, only to find more racial discrimination, but this time in the local gay community. He was often met with cold stares; non-Asian men kept to their own corner, rarely interacting with Asian men.

Christian started drinking with friends, then smoking pot, then experimenting with ecstasy, K, cocaine and crystal meth. Initially he did meth only occasionally but eventually he was doing it every weekend.

When he was high, he would often engage in condomless sex. Looking back, it wasn’t just the drugs that affected his ability to negotiate safer sex, he says, but also the homophobia and racism he experienced: “The use of substances was how I learned to cope with my HIV status and not being accepted by society.”

Twice a year Christian would make sure to go for an HIV test. In 2003, those test results came back positive. Depression hit him hard, along with thoughts of suicide. He took refuge in crystal meth, a habit that grew into an addiction that lasted for seven years. As his meth use spiraled out of control, so did his life. He lost his job, and after bingeeing he would veer back and forth from depression to wanting more meth as soon as he started to feel better.

The path to recovery wasn’t easy. Eventually, after trying to quit on his own and giving treatment programs a few tries but with no luck, Christian went for treatment at the Centre for Addiction and Mental Health’s Rainbow Services Program, which caters to the needs of gay, bisexual and transgender people. Testing positive for hepatitis C around this time helped him realize that his wish to live was much stronger than his wish to die. “Coming out of treatment, I felt pretty good because I wanted a new life.” Soon, he began participating in community work, discovering that he could pursue his life goals and that HIV was not a death sentence.

Christian’s own struggles inform his perspective, which contrasts sharply with conservative views that substance use is simply wrong and deserving of jail time. “We know that the war on drugs has not worked,” he says. “The criminalization of people who use drugs is problematic. Not being able to access harm reduction supplies in the federal prisons is a big problem.” To help people in meaningful ways, he says, “I think we need to come from a place of understanding why people use substances and we need to support people so that they can make their own informed choices.”

Recovery, Christian believes, is a lifelong endeavour, and a big part of what helps him keep moving forward is knowing who has his back. “What I have been able to do quite well is find which communities I belong to. Having the support of friends and family and my partner through struggles and challenges has made all the difference.”

Indeed, finding supportive spaces and engaging in community work have undeniably played a significant role in restoring his capacity to pursue both his personal and professional goals. For this, he credits ACAS and CAAT, two organizations that Christian now calls home, where he can be a proud, gay, poz Asian man, and participate in mentoring and educational opportunities and peer initiatives for newcomers with HIV. Both networks he recently helped establish—the CPPN and OPA—also hold a special place in the heart of a man who has proven his allegiance to addressing the needs of people living with HIV and who is not afraid to join his peers in tackling the hard work needed to sustain the movement.

A huge part of what drives Christian in his work and in his own personal struggles is to make visible the often-neglected challenges of people who have been marginalized. “For me, as an HIV-positive Asian man, I really want to highlight that cultural piece.” Even in a city like Toronto, he doesn’t see many racialized people feeling comfortable with stating that they’re HIV positive. “That adds another layer of shame and feeling socially isolated. You feel no one cares for you. There are so many interconnected scenarios related to someone using substances.”

For Christian, it is his lived experience that drives his activism. “Why am I doing this work? Because I want my fellow peers to be in a better place, to make sure our rights are protected and that we’re not treated differently due to our HIV status.” Unfortunately, he adds, more than 30 years after the discovery of HIV—and 30 years of activism—those living with the virus still face stigma.

He acknowledges a spiritual element to his efforts, springing in part from his mother. A Buddhist nun, she nurtured in him some Buddhist values, including a commitment to help people who are suffering. “There’s something called the Bodhisattva vow, for people who have reached levels of enlightenment. These Buddhas have decided to stay in the realm of Samsara, the human world where there’s pain and suffering, because they want to provide help to other worldly beings as opposed to transcending. That’s one of the values that guides me, because I am a helper and an activist, and I feel like it’s not just about me. It’s about other people, too. It’s about humanity.”

Shazia Islam provides services and support to South Asians living with HIV at the Alliance for South Asian AIDS Prevention. She is also a peer research associate for the Canadian HIV Women’s Sexual and Reproductive Health Cohort Study (CHIWOS).
Ever since the early days of HIV in Canada, local networks of people living with HIV have been the primary drivers of the response to the epidemic. However, Canada has lacked a national network of people living with HIV acting collectively to inform and influence public policies. Until now, that is. Formed in the summer of 2015, and steadily gaining members since, the Canadian Positive People Network (CPPN) aims to respond to the changing needs of diverse communities of people with HIV.

“I have been living with HIV for 25 years, and I’ve been connected to the HIV community in one way or another the whole time,” says Jeff Potts, long-time public health advocate and activist, “but I realized that despite my involvement, I’ve been at something of a distance personally from my HIV-positive peers. Then, the CPPN was born. At long last, we have a network that is unconditionally for us and by us. In the CPPN, I have found my HIV family.”

While remaining an independent grassroots collective, CPPN addresses the needs of people with HIV by building partnerships and influencing policy. To name a few examples from this past year, CPPN partnered with the Canadian Working Group on HIV and Rehabilitation (CWGHR) in a national forum to address ways to ease the burden of limited financial resources experienced by many people aging with HIV. The CPPN was selected to represent Canadian civil society at the UN High-Level Meeting on Ending AIDS in Geneva. And the CPPN is collaborating with HIV-positive youth, the HIV Disclosure Project and YouthCO to develop a workshop that will empower young people with HIV to disclose their status.

Youth are already feeling the impact of this work. As Muluba Habanyama, a member of CPPN’s youth committee explains: “I joined CPPN at a time when I was new to disclosing and advocacy. I craved community involvement and guidance in navigating this complex virus. CPPN really promotes the involvement of people with HIV, which is why I am so passionate about being a member.”

As the HIV movement has become increasingly professionalized, people living with HIV are no longer always at the forefront of the HIV response. CPPN members believe that we need to recommit ourselves to the principles of GIPA and MEPA—the greater involvement of people living with HIV and the meaningful engagement of people living with HIV—to promote access, equity and human rights, and to ensure that government and organizations serving people living with or at risk for HIV are held accountable to the community.

Join us! To learn more about the CPPN or get involved, visit cppnrcps.ca or email cppn.rcps@gmail.com. You can also find us on Facebook and Twitter (@CPPN_RCPS).

John McCullagh, a member of CPPN, is chair of CATIE’s board of directors.
Zak Knowles was diagnosed with HIV in 1990. He did well on treatment and had been living with HIV for almost a decade when he tested positive for hepatitis C. This second diagnosis was far more distressing, Zak recalls, because he didn’t know what to expect of hepatitis C treatments that were available at the time.

In the late 1990s, the only treatment for hep C was a grueling six- or 12-month regimen of injections and pills with severe side effects. To make matters worse, treatment usually only worked about a third of the time for people coinfected with HIV and hep C, forcing many to endure multiple rounds.

Unlike HIV, which attacks the immune system, hep C goes after the liver. Because of Zak’s relatively advanced liver damage, his doctors recommended he start treatment immediately. This meant weekly injections of pegylated interferon and daily ribavirin pills. He tried this treatment twice. Unfortunately, both times he started treatment, Zak experienced dangerous drug interactions that landed him in the hospital. His doctors at the time didn’t realize that ribavirin could interact with his HIV med AZT.

Zak started seeing a coinfection specialist, who switched his HIV medication. After a few months Zak tried hep C treatment a third time. During six months of treatment, he lost his appetite and more than 20 percent of his body weight. “I lived on Ensure,” he says. “That was the only thing I could keep down. That and ginger ale. I kind of became addicted to ginger ale.” He also felt extremely fatigued, sometimes needing hours just to get up in the morning. And the nausea he experienced was so intense that today he says he still has a “Pavlovian response” when he smells rubbing alcohol, which he used to sanitize the site prior to his weekly interferon injections.

Thankfully, his third attempt to clear the hep C virus was successful: In 2005 Zak was finally cured. That period of being on hep C treatment was undeniably “the most miserable time of my life,” Zak recalls. Although he went through hell, he advocates treatment for all people with hepatitis
C—especially since drugs today are nothing like they used to be.

**NEW GAME-CHANGING DRUGS**

Since 2011, a groundbreaking new class of drugs called *direct acting antivirals* (DAAs) has transformed what it means to have Hep C. These drugs don’t cause horrific side effects and the newer ones cure almost every person on the first try. In some cases, treatment is as simple as one pill per day, taken for two to three months. These new medications are truly game-changing, and they couldn’t have come soon enough.

Hepatitis C is a big problem among people living with HIV. In Canada, almost one third of people living with HIV are coinfected with Hep C. Yet for decades treatment was so onerous that many doctors hesitated to put their patients through the ordeal. “The treatments were so miserable,” says Dr. Jordan Feld, hepatologist and researcher at the Francis Family Liver Clinic, in Toronto, but with the new drugs “things have changed dramatically.”

In clinical trials of the latest DAAs, HIV-positive individuals were just as likely to be cured of hepatitis C as HIV-negative people. With so many effective treatments available, Feld predicts that people living with Hep C might be the first large demographic to be free of Hep C. “That might be a bold statement, but I think it is realistic,” he says. “It’s relatively easy to screen people with HIV for hepatitis C, and we can now cure almost everybody of their Hep C.”

He points out that liver disease is now a leading cause of death for people with HIV, and “a lot of that liver disease is related to hepatitis C.” Coinfection can accelerate liver damage, so eliminating hepatitis C from the HIV community would be a major public health achievement.

**GETTING MORE PEOPLE ON TREATMENT**

The first and most important step in curing hepatitis C is getting diagnosed. The Canadian Liver Foundation recommends Hep C testing for all HIV-positive people, as well as all baby boomers (born between 1945 and 1975, including people who have undergone medical procedures or been immunized in countries where hepatitis C is common) and people who have injected street drugs. Despite the high prevalence rate in this country, nearly half of all Canadians with Hep C are unaware of their infection.

“Treatments are fantastic, but they are only great if you get them,” Feld says. Most HIV care providers are aware of screening recommendations, but still too few HIV-positive people are being tested for hepatitis C.

The second hurdle is overcoming the fear and misinformation surrounding Hep C treatment. As Zak Knowles described, “scare stories” about the debilitating side effects of the old regimens seem to have created a lasting negative impression that deters some people from seeking treatment. According to Feld, despite headlines trumpeting a revolution in Hep C treatment, a surprising number of his Hep C patients have no idea that newer, far superior treatment options are now available.

**SPECIAL CONSIDERATIONS FOR PEOPLE WITH HIV**

There are now several interferon-free medications that can cure hepatitis C. The main difference between them is that some work better against certain strains, or *genotypes*. Different regimens also vary in pill number and schedule, but their effectiveness is generally comparable. A medication is chosen based on a person’s prior treatment history, degree of liver injury and Hep C genotype.

For people living with HIV, it’s safest to start Hep C treatment after a few months of consistent HIV antiretroviral therapy. This gives your immune system the best chance at fighting hepatitis C. According to Feld, new Hep C medications are far less likely to cause dangerous interactions with HIV meds, like those Zak experienced more than 10 years ago. People with HIV are also less likely to need to switch HIV medications before starting Hep C treatment, although doctors still need to check for drug interactions with any combination.

Soon new drugs will be able to cure any hepatitis C, regardless of a person’s genotype. These “one-size-fits-most” drugs will make it even easier to treat coinfected patients, says Feld. However, one expected advancement in hepatitis C treatment—even shorter treatment times down the road—is less likely to benefit people with HIV. “When we push the limits of therapy [experimenting with even shorter treatment times in clinical trials], people with HIV don’t do as well,” Feld cautions. To be on the safe side, he says, people with HIV will likely need to be treated for eight to 12 weeks, while others may eventually need only six, or even four, weeks.

While the new generation of Hep C meds represents a major medical achievement, these drugs don’t come cheap, ranging in price from $55,000 to $80,000 for a regimen. These high costs prevent many people who don’t have insurance from starting treatment right away.

People with HIV see enormous health benefits after being cured of hepatitis C. For Zak Knowles, treatment changed his life. Cured of hepatitis C, Zak had far more energy; he could go hiking and enjoy other activities he had given up during treatment. And for the first time in years, he found he enjoyed eating again.

Zak would do it all again if he had to. Fortunately, most people with Hep C today have much better options. Some are still understandably wary of treatment, but Feld likes to remind his patients of the early days of HIV drugs: “Remember how difficult HIV care used to be? Bags of pills, tons of side effects—it was miserable,” he says. “Hepatitis C care has gone through the same revolution, just faster.”
Let's Talk About Sex

Are new options in the HIV prevention toolkit creating a sexual revolution and a new poz identity?

Rob Easton investigates.

Illustrations by Kelly Schykulski
Tara has lived with HIV for 12 years and she’s been a mom for 11. “I don’t know the difference between being a mom and being HIV positive,” she told me over the phone. “For me, they happened at the same time.”

Her voice sounds self-assured, confident. Tara works in the HIV sector, managing a program by and for HIV-positive people, through the Ontario AIDS Network, focused on helping people realize their leadership potential.

When it comes to sex, she says that her confidence comes from the knowledge that HIV is only one part of her life, and mostly her work life at that. The single pill she takes each day reduces her viral load to undetectable levels, which, in turn, makes transmission to her sex partners very, very unlikely.

This knowledge has transformed the way Tara and many others living with HIV view safer sex and what it means to be HIV positive. We now know that in addition to condoms, there are other highly effective ways to prevent HIV transmission. Research has clearly shown that maintaining an undetectable viral load can be an effective strategy (see Treatment as Prevention, page 20), as can the daily use of PrEP by an HIV-negative person (see PrEP, page 22). These expanded options in the HIV prevention toolkit are allowing more HIV-positive people to enjoy happy and healthy sex lives and have opened the door to what some are even calling a new poz identity.

“When I leave work at 5 o’clock, I take my HIV hat off to go be a mom,” Tara says. “That’s my second job. When I go home, it’s not about HIV, it’s about being a mom. And then the next day, I go to work, just like any other working person.”

So, where does sex fit in? Tara is sexually active but, as with any single mom, it’s complicated. “I’ve dated since I had my son. I think it’s hard to find the perfect person—whether you’re HIV positive or not. Overall, my experiences have been quite positive.”
Though Pierre Trudeau once said there’s no place for the state in the bedrooms of the nation, many people living with HIV do feel the presence of the law when meeting prospective sex partners. In Canada, engaging in a sexual activity that carries what the courts refer to as “a realistic possibility” of HIV transmission without disclosing your status beforehand can potentially lead to being charged with a serious crime. Because of this, Tara approaches sex cautiously but she says she has been lucky when educating her partners about the chances of transmission.

“If they don’t want to sleep with me because I’m HIV positive, they’re probably not worth sleeping with anyway,” she laughs. When dating, she follows her own advice from the leadership workshops she delivers—recognizing her own self-worth and that self-confidence goes a long way when it comes to disclosing to a partner. “I know that when my self-esteem was low, I met a lot of frogs,” she says. “When I realized my true worth, so did others.” She also noticed that when she was able to tell people with confidence that she was HIV positive, their reactions improved.

“I met this really amazing guy. I had never been on an online dating site before but on my first try had good luck. He was everything I had ever wanted, a true Prince Charming. I had dated so many toads and finally found my prince.” After their third date, they had a hot make-out session in his car. Tara knew that things could go further and she needed to tell him.

The next time they met, she broke the news to him on a park bench. “One thing I’ll never forget is that he held my hand the whole time, and when I said I was HIV positive, he didn’t let go.” She gave him a few websites to check out if he wanted to learn more about HIV and told him that it was OK if things were over, she would understand. She felt good after the talk. He called her later, asking when they could meet again.

Tara considers herself lucky because many people living with HIV do not even consider sex an option. This is especially true for women living with the virus. One study found that only half of HIV-positive women in Canada are sexually active. Of the 1,213 women from BC, Ontario and Quebec who participated in the Canadian HIV Women’s Sexual and Reproductive Health Cohort Study (CHIWOS), 77% had an undetectable viral load yet 49% were not sexually active. This flags that despite successful treatment and a radically reduced risk of transmission, for many HIV-positive women fear, stigma and other issues may get in the way of a satisfying sex life.

Psychologist Trevor Hart, director of Ryerson University’s HIV Prevention Lab in Toronto, says that fear of disclosing one’s HIV status and fear of rejection prevent many people from being assertive about their wants and desires. This, in turn, gets in the way of their sexual health and satisfaction. “I try to help people who are HIV positive improve their coping and assertiveness skills so they don’t feel like they are less than just because they’re living with HIV. They’re the same person they always were except they’re also living with HIV.”

People with HIV have every right to intimacy, pleasure and living the same full life as they did when they were HIV negative, Hart adds. When people learn to be more

### Treatment as Prevention

Research has shown that taking HIV treatment every day as prescribed and maintaining an undetectable viral load not only protects your health as a person living with HIV but it can also radically reduce the risk of HIV transmission. This is called treatment as prevention (TasP).

TasP has made a huge difference in the lives of serodiscordant couples—where one partner is HIV positive and the other is HIV negative—because it helps relieve the potential anxiety that one or both partners may have about transmitting the virus.

**What does undetectable mean?**

When HIV treatment is taken consistently, it can cause the amount of HIV in your blood (your viral load) to drop to levels so low that the most sensitive HIV tests cannot detect it. The virus is still there but is undetectable.

In Canada, undetectable is usually defined as fewer than 40 to 50 copies of the virus per millilitre of blood. This is a far cry from the 30,000 or 40,000 copies per millilitre of blood a person with a high viral load can have.

**How well does TasP work?**

If you maintain an undetectable viral load, your chances of transmitting HIV to a sex partner are extremely low.

For TasP to be effective, an HIV-positive person must maintain an undetectable viral load. Most people can achieve this by adhering to their HIV meds and seeing a healthcare provider regularly to monitor their viral load. Your healthcare provider can also offer testing and treatment for other sexually transmitted infections (STIs), as well as ongoing adherence and risk-reduction counselling.

If you are in a sexual relationship with an HIV-negative person, your partner should also get tested regularly for HIV and other STIs. If you are just starting HIV treatment, your HIV-negative partner can go on PrEP for six months while your viral load gets down to undetectable.

To provide an extra layer of protection from HIV and protect you from other STIs, you can also use condoms.

If your viral load rises due to missed doses (poor adherence) or treatment failure (in rare cases ART stops bringing the viral load down to undetectable levels), this can provide a window of opportunity for HIV transmission. Having another STI may also increase the risk of transmission.
assertive, they are happier and more resilient and tend to make better choices about their sexual health.

Tara found that recognizing and overcoming the stigma she had internalized about her own HIV status was the first step. Once she felt more comfortable and at ease about having HIV, she was able to be more assertive and normalize it for her partners. Her self-esteem has improved because she is no longer anxious about passing the virus to her sex partners. She knows that her undetectable viral load makes the chances of that super slim.

In recent years the use of HIV treatment as prevention (TasP) has gone a long way toward giving peace of mind to people living with the virus. In fact, experts say that the chances of passing HIV during sex are lower for an HIV-positive person with an undetectable viral load than for someone who believes they are HIV negative but may not be. When a serodiscordant couple also uses other forms of prevention, such as condoms or PrEP consistently and correctly, the risk of transmission is close to zero.

Using TasP and PrEP, in addition to condoms, as strategies that dramatically reduce the risk of HIV transmission is changing the way some HIV-negative people view people living with the virus. “A person with HIV is no longer necessarily seen as a threat,” says Joanne Otis, researcher and professor of sexology at the Université du Québec à Montréal. “For many people living with HIV, these prevention strategies have truly reopened the door to having a sexual life. However, at the same time, some people don’t yet understand that an undetectable viral load significantly reduces the risk of HIV transmission. This information has been published, but HIV-negative people are still sometimes fearful of having a sexual relationship with an HIV-positive person.” Otis hopes, and strongly believes, that our new understanding of HIV prevention will continue to reduce HIV stigma.

Rick has seen HIV stigma shift and morph over the years. About to mark 30 years since he was diagnosed with HIV, he says that the stigma he experienced at the start of the epidemic continues to influence his outlook. But, he says, it is certainly possible to have a happy sex life as an HIV-positive person.

Before we met for the first time, he told me he would be easy to spot. He sports an eye patch over his left eye, which covers injuries he sustained in a “poorly planned out” suicide attempt when struggling with depression in the early days of AIDS. For Rick’s generation of long-term survivors, the idea of having a healthy sex life sat at the end of a list of hopes and goals that started with simply staying alive.

When he was diagnosed with HIV in the mid-’80s, Rick retreated into his shell. “At first, I thought I was dying, so dating was not a priority,” he says. “So many guys were dying that by the second or third year, I decided I wasn’t going to make any more gay friends because I couldn’t watch one more friend die.”

Despite his grief and his expectation that he would soon become ill himself, Rick eventually met a new partner who told him he was HIV negative. More importantly, for their relationship, this man did not hold the same fear and stigma around sex and HIV that so many others had. “Sex was just a natural thing for him,” Rick says. “It was all about exploring and having fun. No shame, no inhibition. It’s hard to find guys who don’t have any shame or inhibition at all, because it’s so engrained in our culture.” They shared a strong connection, both in and out of the sheets. That was what allowed Rick to regain his sexual freedom, long before the age of TasP and PrEP.

After seven years together, Rick’s partner fell very ill. He had lost a lot of weight and was dealing with serious mental health problems caused by meningitis. Rick was able to gain power of attorney and put him in the hospital. That’s when he found out that his partner was not HIV negative after all—he had full-blown AIDS.

His partner’s deteriorating health came as a shock, but luckily it was 1996 and the first drug “cocktail” was coming out, just in time to save his life.

Rick believes that the reason his partner avoided getting tested back then was stigma. He believes that his
partner, and many others like him, didn’t get tested so he could avoid the dreaded possibility of being HIV positive. Though HIV-positive people are now living long and well, he says, fear and stigma help keep the epidemic alive. Treatment as prevention and PrEP allow some gay men to have sex with less fear, “in particular guys who find themselves barebacking or who are in magnetic (serodiscordant) relationships.” But he views stigma as being the big issue.

Rick sees the ongoing evidence of stigma in his work as coordinator of Gay Poz Sex (GPS), a program that seeks to improve the sex lives of HIV-positive gay men. He says that HIV stigma and fear prevent poz men from making sex- and health-related decisions that would lead to the outcomes they want. Social media are providing more opportunities for sexual connections but don’t always lend themselves to meaningful conversations or connections.

Rick says that a healthy, happy sex life is about physical and emotional intimacy, trust and knowing how to ask for what you want: “It’s about your own comfort level with yourself and exploring your sexuality and what it is that you like. It’s hard to set boundaries if you don’t actually know what you’re into.”

Trevor Hart stresses that a sense of empowerment can help a person living with HIV move beyond the negative feelings that stigma can incite. It helps people “to assert themselves sexually,” he says, “to get what they want out of sex, whether it’s intimacy or pleasure, or other things. People also feel empowered to make safer personal decisions about their sexual health.”

Both Joanne Otis and Trevor Hart agree that one’s physical health, sexual health, well-being and happiness are inextricably linked. “A combination of those elements help you meet your social and sexual needs,” says Joanne.

“...It was a self-fulfilling prophecy...” Jonathan Postnikoff told himself the day he tested positive for HIV six years ago, his thoughts spiraling out of control. “‘You’re that little gay boy who grew up fearing HIV and now you’re positive.’ That fear was something I’d been taught to feel. That if you have HIV, you’re somehow dirty,” he told me over the phone from Vancouver.

The fear of becoming HIV positive ran deep and took time to recover from. Today things are very different. Jonathan now identifies openly as an HIV-positive and undetectable

### PrEP

PrEP (pre-exposure prophylaxis) is the use of the HIV medication Truvada by an HIV-negative person to prevent HIV transmission. With Health Canada’s approval of Truvada for this purpose in February 2016, the drug will likely soon become more widely available to HIV-negative people (it was previously used only to treat HIV).

At the time this article was published, the daily use of oral Truvada is the only type of PrEP that has been found to be effective in multiple studies. However, other forms of PrEP are being investigated and may become available in the future.

**How well does it work?**

PrEP has been called a game-changer because it can drastically decrease the chance of HIV transmission during sex. When taken correctly and consistently, Truvada is a highly effective HIV prevention strategy. If it is taken every day and used with treatment as prevention or condoms, the chance of transmission is reduced even further.

**What happens if someone forgets doses?**

If a person forgets to take their PrEP pills, the chances of transmission increase. Also, Truvada is not effective against strains of HIV that are resistant to Truvada. For example, a Canadian man who was taking PrEP religiously became HIV positive with a drug-resistant strain of the virus.

While PrEP is a highly effective strategy for preventing HIV, it does not work against other sexually transmitted infections (STIs). It is therefore recommended that PrEP be used along with condoms.

**Who can take PrEP?**

- PrEP should only be taken by people who are HIV-negative and at high risk for HIV—for example, people whose sex partners are HIV-positive and have a detectable viral load or people who have condomless sex with partners of unknown HIV status. (If an HIV-positive person takes Truvada without other HIV drugs, they could develop a drug-resistant strain of the virus.)

**Why is it important to see a doctor regularly?**

Guidelines recommend that a person on PrEP see a healthcare provider regularly to check in about taking the medication on schedule and for risk-reduction counselling, as well as regular HIV and STI testing. The healthcare provider can also work with PrEP users to keep an eye out for possible side effects and drug toxicity.

**Is the cost covered?**

Only Quebec’s provincial health plan currently covers the cost of Truvada for PrEP. People with workplace drug plans may have access to PrEP through their private insurance (check with your provider). Status First Nations people and Inuit are already covered under the Non-Insured Health Benefits (NIHB) Program.
Condoms

Condoms have been a mainstay in the safer-sex toolbox since long before the HIV epidemic, and they continue to play an important role in preventing HIV transmission.

How well do they work?

In addition to preventing pregnancy, condoms remain a highly effective way to prevent the transmission of HIV provided that they are used correctly and consistently. Condoms—both external (male) and internal (female)—create an impermeable barrier that prevents the exchange of fluids between sex partners. HIV, which can live in vaginal and anal fluids as well as in semen (including pre-cum), cannot pass through latex or polyurethane condoms. Condoms are also the only effective way to prevent many other sexually transmitted infections (STIs), such as syphilis, gonorrhea, herpes and chlamydia.

Using condoms in combination with treatment as prevention or pre-exposure prophylaxis can further reduce your risk of contracting HIV. So, it is in your and your partner’s interest to keep condoms in your toolbox of HIV prevention strategies.

(Note that lambskin condoms do not reduce the risk of HIV and other STIs.)

Are they foolproof?

No. Although condoms are impermeable to HIV, they can fail if they break, tear, slip or leak during use. This can give HIV the opportunity to catch a ride with any fluid that makes its way through. This is why correct condom use is critical, especially when other prevention strategies are not part of the picture. You can reduce the chances of this happening by knowing how to properly put on a condom and use it during sex.

Getting it on right

Here are some tips for using external condoms:

- Store condoms at room temperature and never use one past its expiry date.
- Put it on before you put it in! It may sound obvious but slipping it in for just a moment can give many STIs the perfect opportunity.
- Open the package carefully, making sure not to tear the condom.
- Place the condom on the tip of the penis the right way around!
- Squeeze the tip of the condom to remove air and leave space for semen. Then unroll it all the way to the base of the penis.
- Make sure you’ve got the right fit and feel.
- Have fun!
- Use one condom per use, per partner. Don’t recycle! And don’t double up: Two condoms together can tear.
- Use lots of lube. Water- or silicone-based lubricants only though—other types can weaken the condom.
- Immediately after sex, hold onto the condom while pulling the penis out of the vagina or anus.
- Carefully pull off the condom when there is no further contact with your partner’s body.

Internal condoms have a closed inner ring that is inserted into the vagina or anus before sex. They can provide similar protection. Be sure to use it instead of, not at the same time as, a traditional external condom.

Practice makes perfect!

Studies have shown that repeated condom use tends to reduce the number of condom failures over time. Water- or silicone-based lubricants not only make sex with condoms more fun, they also decrease the likelihood of tears by reducing the amount of friction applied to the condom.

Gay man, which allows him to cut to the chase and find what he is looking for online, whether it’s sex or dating or true love. “I put my status out there because I want to weed out the people who won’t talk to you because you’re positive.”

Being open and upfront about his HIV status also attracts the type of men he wants: those who are either undetectable like him, on PrEP or just open-minded and willing to learn. It also gets the conversation about HIV and STIs started, which ultimately destigmatizes them. “If he has no STIs and I have no other STIs,” Jonathan says, “then the risk of contracting or transmitting HIV is close to zero. If the guy’s upfront and says, ‘I’m on PrEP,’ and I say ‘I’m poz,’ that’s it. That’s the end of the conversation.”

Jonathan points out that guys who are on PrEP must adhere to their meds and monitor their health similar to the ways that HIV-positive people do, with regular check-ups to test for HIV and other STIs. This makes them more aware of their health. “When I’m cruising online and see that someone is on PrEP, it relaxes me and puts me more at ease. It’s an indicator that this guy has done his homework and knows what he’s talking about. That’s the type of guy I seek out.”

He believes that the future is bright for people like him who live in cities where HIV-positive people can expect a degree of understanding and openness to the changes that are happening in HIV treatment and prevention. “When I seroconverted I thought I would be single for the rest of my life. Now seeing the possibilities out there makes me a lot more hopeful that I won’t be single forever,” he laughs.

But that optimism about his own romantic future needs to be expanded beyond the bright lights of the big city to everyone living with the virus, including those in small towns and rural areas. “We still have lots of work to do to make that a reality for everyone living with HIV.”

Rob Easton is a freelance journalist, filmmaker, Trekkie and dog owner. He is also the former host of the TV show Don’t Quit Your Gay Job.
Addictions

A neuroscientist, a peer navigator and a psychoanalyst offer their insights and advice.

BY RONNILYN PUSTIL AND DEBBIE KOENIG

MARC LEWIS
Neuroscientist and professor of developmental psychology
Radboud University, Holland

There’s no doubt that addiction causes changes in the brain and that there’s a physiological substrate to falling in love with substances. But addiction is not a disease. My main argument is that the brain is changing whenever we learn anything. And the more intensely we learn something, the more our neurocircuitry changes. That happens when you fall in love or join a religious order or become a sports fan. With addiction, it’s the repeated pursuit of a particular goal (heroin, alcohol, crystal meth ...) that causes recurrent changes and gradually grows a network of brain connections that support that behaviour and make it seem like the only game in town.

There’s no doubt that the brain changes. But the medical model, the dominant model which views addiction as a disease, has a fatalistic quality to it. The implications of the medical model—that addicts need medical treatment and that going into
There are good neurobiological reasons for that: dopamine, dopamine.

Dopamine is a neurochemical that is sucked up into the reward centre of the brain. When people have very powerful goals that are attractive to them, one of the things that dopamine does is focus all your attention on the present tense and what’s right in front of your face. That makes it very hard to get a perspective that will lead you to think of tomorrow.

When people become addicted, neuroplasticity works in a particular way: Your brain starts to rewire in terms of that particular goal. The good news is that when you go through recovery, neuroplasticity is ongoing. You continue to rewire, resculpt, reshape neural pathways throughout your life, as long as you continue to learn. Neuroplasticity plays an important role in all kinds of healing, including addictions, which is very hopeful.

Addicts find it very helpful to recognize that there is a biological substrate. So it’s not that you’re such an awful person, but rather, you got stuck in a biological feedback loop that is difficult to break out of. But the brain is plastic and the feedback loop can be altered.

Interrupting the cravings can be a dramatic moment or a process. I’m in touch with thousands of addicts around the world and sometimes people relapse again and again and again and finally they say, “F*** this, I’m just not going to do this anymore. It’s just too awful.” Others just stop suddenly and never use again, and there’s every gradation in between.

**ANGELA THOMSON**
Peer Navigator, St. Paul’s Hospital, Vancouver

In high school I turned to alcohol to relieve the emotional pain of losing my father, who passed away after two years of battling cancer. My mother had struggled with alcoholism her whole life and died in her early 30s while living on the streets of downtown Vancouver. I grew up not knowing my mother and only remember seeing her a few times. I was 14 years old and just starting junior high when I was told of her passing.

I had no concept of what I wanted to be or who to trust. I thought my destiny was to drink myself to death. Then I turned to drugs, initially smoking marijuana in high school. After graduating, my drinking continued but I managed to keep it under control.

At a cabaret one night I met the man who was to become the father of my two daughters and we were together for seven years. After giving birth I continued to drink, eventually finding myself in a treatment centre...
after a family intervention. It was there that I was introduced to Alcoholics Anonymous and managed to maintain my life, some sanity and my sobriety for almost four years.

Then I found myself missing the chaos in my life. I left my relationship, took my daughters and went to live with my brother, who was drinking heavily at that time. I eventually picked up a drink again when I was 27 and I was off to the races. I gave my daughters back to their father and went to a party that lasted for six years. I got into unhealthy relationships and did things that I never ever thought I’d do.

I was introduced to intravenous drug use by one boyfriend, which began a downward spiral that saw me committing petty crimes to support my cocaine and heroin addictions. After six years living day by day on the streets or on other people’s couches, I ended up in the same place my mother had been before she died—desperate, hungry, lonely and tired. One day I called a women’s recovery house in Surrey and was told to get there as soon as possible if I wanted a bed to sleep in.

Once there, I stayed clean for 30 days. After some blood work, the house doctor explained that I was HIV positive. It was January 1997. I was in shock. In the recovery house there was no privacy, so my condition became common knowledge. There were other girls who were HIV positive so they were somewhat of a support; one even took me to a support group for HIV-positive people.

Once out of the recovery house, I focused on staying clean and sober, went to AA meetings and tried to be the best mother I could be. My main inspiration for staying away from drugs was my desire to be a mother again.

I have managed to stay sober since October 10, 1997, with the help of many healthcare providers, AA and some very close loving friends. My health has been relatively without scare. I continue attending AA meetings to help with my mental and emotional well-being.

AA allows me to walk into a room without feeling judged for my addictions; however, I don’t talk about my HIV at meetings. I keep that for the select few I trust. I have seen AA members who were open about their HIV diagnosis and then felt like outsiders, some eventually falling back into addiction. A handful of my friends gave up on their health due to being HIV positive. I definitely don’t want to go out and kill myself due to my addiction or my HIV. Right now my sobriety is the most important thing in my life—without it I have nothing.

After establishing relationships with nurses and doctors at St. Paul’s Hospital, I was offered a position as a peer navigator. In my work I support others who are HIV positive, many of whom also live with drug and alcohol addictions. I always share my story with clients and tell them I am sober. If they need help with drinking or drug issues, I direct them to the proper services. Doctors, nurses and social workers ask for my support when we have a newly diagnosed client who needs someone to hold their hand. I love my job helping others and hope that one day people will understand that they can be anything they want.

To anyone who doesn’t believe they have a life because they are HIV positive and struggling with an addiction, I want them to know that I went back to school and completed my Associate Degree and have almost completed a bachelor of social work. Life is good and I am very grateful I am alive and was given another chance.

**MARCO POSADAS**  
Clinical social worker and psychoanalyst, Toronto

I prefer to stay away from using the label “addict,” as it helps in my psychotherapy work with gay, bi and...
other men who have sex with men, many of whom are struggling with trauma and some of whom are HIV positive and use substances as a way of coping. The idea of an “addict” has so many negative connotations. People with these histories may already be marginalized due to their different identities (race, class, sexual identity, gender performance, ability, etc.), and already experience a lot of prejudice. I don’t want someone to worry that I’m going to think of them as an addict, and I find it easier to address the problematic aspects of substance use when we open a space to explore what this means for them.

Many people who are struggling with substance use have histories of emotional and mental health needs. I also stay away from the term “mental illness” and frame it in terms of mental health promotion. Substances are more often than not used to deal with intrapersonal, interpersonal and other types of social stressors. Oftentimes clients come in seeking treatment with the idea that the substance is the problem, but as the therapeutic relationship develops, we see that it is something that actually helps them cope. When substance use becomes the only way that they have of coping, then it can become problematic.

For example, if someone needs to use a substance because otherwise he doesn’t know how to handle himself at a party in the first three years after an HIV diagnosis, then the issue may not be the alcohol itself but the problems that the person is having coping with his diagnosis. In our North American society, we tend to push for quick solutions, and sometimes alcohol and substances offer that “quick fix.” When we talk about how the substance helps the person cope, we are able to talk about underlying issues they are struggling with and find strategies that can help them cope in more effective ways.

I find it’s easier for people to start working through their difficulties when the substance doesn’t get demonized. When the substance gets stigmatized, the substance user gets demonized, too, which usually leads them to become more isolated and sometimes ramp up their drug use. If I feel embarrassed about the way that I cope and I don’t have a way to articulate that concern, I may be pushed to use more as a way to regulate my nervous system (anxiety). The substance may make me feel less alone. If I am dealing with constant rejection on Grindr because of my HIV status, for example, the substance may hold a special place as I know it will always be there for me and never turn away from me.

What I find most useful for people who self-identify as having a problem with the way they use substances is a combination of group work and individual psychotherapy. That way they can process in their individual psychotherapy some of the stuff that comes up for them when they are in a group. The experience of being in a group really helps a person normalize the experience of using substances as a way of coping and decreases the chance of using that usually leads to relapsing. Dealing with the shame in a group context is very powerful. A group also offers a supportive network that can have some of the functions that the substance had for them.

In a nutshell, what helps people “kick their addiction” is an understanding of how they’re using the substance to cope and substituting that way of coping for something that makes them feel more empowered. For example, a person might identify that they get the same sense of relief from a close, warm and kind connection with a friend that they get from using substances. Understanding the patterns of use, the triggers and the consequences usually helps people to make different choices.

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**Survey Says…**

Since its inception in 1990, CATIE has shared health information with people living with HIV so that you can make informed decisions and take better care of your health. Publications like The Positive Side also connect people living with HIV from across the country. We aim to deliver the stories and information you want and need.

In 2015 CATIE launched an online survey to better understand the information needs of people living with HIV. We asked questions like: What do you want to know about HIV treatment? How important is information about mental health and sexual health? How important is it to you to hear the personal stories of others living with HIV? Some of you, dear readers, participated. We thank you!

Your answers were as plentiful and diverse as the people who live with HIV. We were delighted by the overwhelmingly positive feedback and plan to follow up on your suggestions. Your feedback helps us produce resources that continue to meet your needs.
Once upon a time, on a green and mountainous island where eagles soar among rainbows, there lived a fierce warrior woman. Threatened from all sides by a dreaded plague, she battled for her life by conjuring up from her soul a series of wondrous works of art. So fierce was the battle between life and death, and so fertile her imagination, that the creative process consumed her, and rather than the gloom of death, she lived...

Art gave and restored life to Salt Spring Islander Margarite Sanchez.

As a child, she recalls that she was “always good with her hands” and she dabbled in drawing, painting and ceramics. Her early attempt at batik, a wax-resist technique for dyeing fabric, was hung in front of the principal’s office at school—as she says, “the first recognition of her potential” as an artist.

Mostly self-taught, Margarite has experimented in a wide variety of art forms and media throughout her life. Now in her 50s, she has come to believe that her art is all-encompassing, that it is present not only in her drawings, photos and paintings, but in all the tasks of her daily life on this rugged West Coast island. There is no division between her art and her life, they are one and the same. They
together constitute a harmonious, even spiritual, whole.

As a young single mom with two children in the late 1980s, Margarite rented a small house on the bay at the southern end of Salt Spring Island, one of the picturesque Gulf Islands tucked between mainland BC and Vancouver Island. Tugboats bobbed in the water, seals and otters played on the beach, and the inhabitants saw themselves as custodians of the land, clearing the beaches of debris, watching over the terrain and the wildlife. “I thought I would live here till I died,” recalls Margarite with a rueful laugh. “I didn’t realize how close to the truth that would be.” But the area was owned by a logging company and in the late 1990s, though not without a fierce struggle by the islanders, the families that lived here were evicted from this Garden of Eden and had to establish new homes elsewhere on the island.

A few years earlier, in the early ’90s, Margarite had begun dancing with a modern dance company. While rehearsing for a performance, she began to notice how easily she became fatigued. She was losing weight and had recurrent candida infections. Doctors’ appointments and various tests turned up no explanation for this change in her health. Eventually she requested an HIV test, “to put my mind at ease.” No one expected that her test would come back positive, least of all Margarite. But it did. She had 50 CD4 cells. AIDS.

Her journey with dance came to an abrupt end, and four years of illness and hospitalization followed. Margarite battled waves of opportunistic infections—Pneumocystis pneumonia (PCP), cryptococcal meningitis and two bouts of cytomegalovirus (CMV), one in her retina. Initially reluctant to start antiretroviral therapy, Margarite began taking HIV meds in 1997.

Slowly, as her immune system rebounded and her vitality returned, Margarite found she was even more driven to express herself through her art. First she tackled life drawing in pencil and charcoal with a small group of artists who hired a model each week for a couple of hours. The focus and meditative quality of drawing created a healing refuge for Margarite, “a time for myself.”

As her health improved, she moved into landscape painting, returning to the site of her first home, to sketch en plein air, reconnecting with the life force of nature that nourishes her spirit. When speaking of this wild part of the island, Margarite refers to it as her “muse,” her “little piece of heaven.”

The collective of artists, known as the Mardi Mob, with whom she has become associated, introduced her to portraiture. Her first portrait was so successful in capturing the mood of the model that Margarite was hooked. “Portrait painting has all the elements of composition, planes and angles, tonal values and colours, plus personality,” she says. “If you don’t capture the personality, you don’t get a sense of the person. More than a resemblance, a portrait needs to be interesting.”

While much of her drawing and painting is done as “playtime” and “for self-care,” Margarite also creates political art and activist statements related to her experiences of living with HIV. She characterizes these works as “catalysts for change” and “an education for the viewer.”

When Margarite and Kath Webster, another West Coast woman with HIV, both achieved undetectable viral loads at the same time, they marked this milestone by creating a large collage they call “Our Journey through AIDS,” which was exhibited at Vancouver’s Roundhouse and Grunt Galleries.
in late 1997. “It had IV poles with drips, pill mandalas, a tiny Buddha, marijuana leaves...everything on it!” Margarite laughs.

Another work, an installation piece composed of Margarite’s empty HIV pill bottles and articles about HIV, entitled “No Longer Naïve” (a reference to the term treatment-naïve to denote someone who hasn’t yet taken HIV meds), was presented at the AIDS Vancouver Island annual art auction. A collage created with other local HIV-positive women exploring the issue of HIV criminalization was shown in 2013 at the Canadian Association for HIV Research (CAHR) conference and at the Positive Gathering, Positive Living BC’s conference by and for people living with HIV.

On a 2013 trip to Buenos Aires with her husband of 25 years, Margarite shot photos that captured the city “from the back seat of whatever public transportation we happened to be taking.” They were staying in the blue-collar neighbourhood, where her husband lived as a child and she wanted to show the gritty side of the city that most tourists don’t see. She also shot video of Las Abuelas (the Grandmothers) of the Plaza de Mayo, who since 1977 have been demanding that the Argentinian government return children who were kidnapped by the military junta during Argentina’s “Dirty War” to their families. She plans to have a show of her photographs along with video footage of the demonstrations in the Plaza de Mayo, in front of the government buildings, with Las Abuelas holding banners and photos of their loved ones who “disappeared.” The opening event will bring together local tango dancers and live music performed by her husband. “I have more ideas than energy, unfortunately,” she chuckles.

Margarite’s artistic life knows no bounds; it extends to her kitchen and beyond. Living in a micro-climate where it is possible to grow food all year round, she sees the cyclical work of gardening, preserving, canning, freezing, drying and fermenting as part of her artistic life. “Particularly as the harvest builds up over the summer, parts of our house become like a still life, full of colours and textures. In addition to the beauty of the harvest, I think about food security, and the fact that so many people with HIV lack food security.”

“As the years pass, I have come to see my whole life as a real-time, interactive art installation,” she continues. “I live openly with HIV now that my two children are grown up. I run a home-based business with my husband who is a silversmith. I’m politically involved with the Green Party and helped to create the petition that our MP Elizabeth May presented in Parliament for a national AIDS strategy. I’m one of the founders of ViVA, an online advocacy and peer support network for women living with HIV in BC. I’ve been involved in several peer support initiatives that have touched the lives of hundreds of positive women over the years.”

When asked what sustains her, Margarite answers without hesitation: “I enjoy eating homegrown food and drinking Argentinian wine. I love the planet. I have an optimistic view of life. That doesn’t mean that bad things don’t happen. I’ve experienced very difficult things in my life, but I honestly feel I am living an enchanted life with AIDS.”

Darien Taylor is CATIE’s former Director of Program Delivery. She co-founded Voices of Positive Women 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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