

SPRING/SUMMER 2021 VOLUME 23 ISSUE 1  
HEALTH INFORMATION & VIEWS

# THE POSITIVE SIDE

**Party n' Play**  
Reducing the risks

**Adoption and Surrogacy**  
What are your options?

**HIV Activism**  
Stories from the front lines

## Confession, Care & Community

Dee Stoicescu on using  
art to find herself

# Growing your Family

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## EDITOR'S LETTER

The past year has brought a lot of changes. The COVID-19 pandemic and the Black Lives Matter movement have prompted us to stop and think about what we take for granted. They've shown us that health, safety and freedom are basic rights that many people don't have. They've also shown us that addressing these problems needs collective action—when it comes to urgent social issues, we all have to do our part.

In this issue we're reflecting on where we are and thinking of how to move forward. In "My Generation" a diverse group of older and younger HIV activists talk about what activism means to them. Closer to home, "Chatty CATIE" celebrates our 30th anniversary by looking back on our activist roots. Elsewhere, we hear from activists and community workers who are grappling with Canada's overdose crisis: in "Getting Started," harm reduction activist Matt Bonn gets the scoop on what it takes to set up a supervised consumption site, and in "Party Time" we look at harm reduction for Party n' Play (PnP). Here you'll learn how community members and HIV organizations tailor supports for guys who use drugs during sex, and if you party, we have some practical tips to keep yourself safer. In "Sex in a Pandemic" we also have a guide for having sex during COVID-19.

Here at *The Positive Side* we love to share your stories. In "The Parent Trap" we hear from people who have explored adoption and surrogacy, and we take a closer look at how—even though people with HIV have increasing options—some barriers to parenting remain. Finally, our cover star Dee Stoicescu talks about their art practice in "Art Posi+ive," showing how they found identity, community and their creative voice.

We hope you enjoy the Spring/Summer 2021 issue! If you would like to contribute to an upcoming issue, then get in touch—we're always looking to hear from our readers (yes, even you!). Got an idea for a topic you'd like to read about? Send any thoughts or suggestions to: [contribute@positiveside.ca](mailto:contribute@positiveside.ca).

—Dan Udy

# THE POSITIVE SIDE

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# Digital Delivery

COVID-19 has forced many healthcare providers to deliver their services by phone and video. Wellness Wheel in Saskatchewan had pioneered this approach before the pandemic—

**Jennifer McPhee** talks to Susanne Nicolay to find out more.

**A**t the start of the COVID-19 pandemic, healthcare providers across Canada switched to virtual healthcare. This shift has led to services that better serve the needs of patients, says Susanne Nicolay, a nurse based in Regina. Nicolay is clinical coordinator and nursing lead at Wellness Wheel, a mobile healthcare service

serving Indigenous people who live on reserves and in cities and towns across Saskatchewan.

Before the pandemic, Susanne's Wellness Wheel team drove between 19 Indigenous communities to provide HIV and hepatitis C care. They also provided general health care and treated other diseases in about four

of these communities. Through their work providing mobile care, the team already had some experience with virtual healthcare; they texted to confirm appointments, and they offered video calls to patients. These services had some limitations, though. Patients still had to book appointments and make their way to a health centre that

offered the virtual care service. Once there, they could see Wellness Wheel's staff on a TV screen. This was not great for people who lived far from a service location, or who did not have access to a car. But it was the only virtual option that doctors could bill for in the province.

In November 2019, Wellness Wheel decided to test a virtual platform called OnCall. This provides secure text and video messaging between patients and their healthcare team. At the time, Wellness Wheel could not bill the province for OnCall visits. Nicolay would travel to a community and see a patient at the health centre or find them in the community. Then, she would use OnCall to talk to the doctor about any issues outside her area of expertise. She began to see more people where it was easiest for them, such as in their house or car. The platform also meant Wellness Wheel's doctor no longer had to travel as often and could spend the extra time treating more patients.

When the pandemic hit in March 2020, First Nations governments closed their communities to outsiders to protect themselves from COVID-19. At first, Wellness Wheel staff worried about how to adapt their services so that they could keep meeting their clients' needs. However, the Saskatchewan Ministry of Health quickly increased the ways that healthcare providers could communicate with patients and get paid. As a result, Wellness Wheel staff were suddenly able to bill the province for their virtual services. These included healthcare services they provided through phone calls, virtual platforms and text messages. Since many local healthcare centres in Indigenous communities fully or partly shut down when the pandemic arrived in the province, Wellness Wheel staff filled the gap. They expanded their services and began to treat people for all their health issues virtually.

For example, Wellness Wheel saw lots of patients with wounds caused by diabetes. Patients often sent photographs of these wounds to staff by text. "It wasn't 100 percent by the book and in an ideal world, we wouldn't do that," says Nicolay. "But in an emergency,

you can't prioritize confidentiality and not provide care to someone." To protect patient privacy, staff came up with ways to make sure they were texting the right person. They also knew it was possible that someone else might get a patient's phone and read their messages, says Nicolay. "In COVID, you had to get creative. I didn't say 'How are your HIV medications?' I would say 'How are the three pink pills we gave you?'"

In many ways, the pandemic has made it easier for people to get medical help. Virtual care is accessible for those who cannot easily move around because of health issues. It is also easier for people without transportation. And it allows more people to get medical help exactly when they are ready and feel safe enough to do so, says Nicolay. She explains that virtual care also protects patient privacy and reduces stigma. Patients don't need to go to a healthcare centre or clinic where they could be seen receiving HIV care. This is an even bigger issue in places where everyone knows each other.

In North America, healthcare is what's easiest for providers. Virtual care makes it possible to do what's easiest for patients.

In North America, healthcare is set up for what's easiest for healthcare providers. Virtual care makes it possible to do what's easiest for patients. Often, healthcare providers expect patients to travel to clinics or hospitals between certain hours. Many don't provide care on weekends, after hours or during lunch. "Healthcare providers also want the four walls, the exam bed; they want all their tools," says Nicolay. "But really, there's a lot we can do in the back seat of a car."

"Yes, certainly sometimes people need to be examined. I am not saying that's not important. But we also have to think about whether we want people to drive four hours for a 20-minute appointment. Or do we want to be respectful of their time, so they feel valued? Not everyone feels safe going to a hospital. Not everyone has sick time or transportation that is easy to arrange. We think we need to lay eyes on people every few months. You may want to physically see people every year, but in between, you could see them by phone or using OnCall. It's possible now and we need to be open to this."

Virtual care has also made it possible to increase people's access to medical help by enabling different types of healthcare providers to work together. For instance, Wellness Wheel provided a tablet for a pharmacist in Regina that is located near a community organization that offers free meals and harm reduction supplies in a safe, accepting atmosphere. When people are ready to begin or restart HIV treatment, the pharmacists use the tablet to make on-the-spot virtual appointments with a member of the Wellness Wheel team.

Healthcare providers need to be open to these kinds of relationships, says Nicolay. "Because, if someone is never going to come into your office, it's not helpful to believe they're just not interested. That's not usually the case. They just may not have the ways and the means." +

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



**A** supervised consumption site (SCS) is a legally sanctioned sterile environment where people consume illegal drugs. These spaces offer drug equipment, connection and staff equipped with naloxone and/or oxygen to reverse accidental overdoses. They also provide access to other services for people who use drugs such as primary healthcare and substance use treatment.

As the COVID-19 pandemic has unfolded, this difficult but lifesaving work has been more important than ever. Harm reduction measures like SCS are proven to prevent overdose deaths. They can also prevent hepatitis C and HIV transmission. Because the pandemic has disrupted harm reduction services, people who use drugs now face greater risk of accidental overdose, HIV and hepatitis C.

Harm reduction is backed by evidence, but many harm reduction workers still face challenges in setting up and running a SCS. They must apply to the federal government for an exemption to the *Controlled Drugs and Substances Act*, which is a long and difficult process. Overdose prevention sites (OPS) are another type of space where people can safely use drugs. To legally operate, OPS can apply for short-term exemptions from their regional government. These are generally granted quickly in response to urgent community needs.

We spoke to staff at two SCS—Prairie Harm Reduction (Saskatoon) and Dr. Peter Centre (Vancouver)—to hear how they got started.

#### **SASKATCHEWAN'S FIRST SAFE CONSUMPTION SITE**

Jason Mercredi is the executive director at Prairie Harm Reduction, an organization in Saskatoon serving communities at risk of HIV and hepatitis C. After four years of research and advocacy from Mercredi and his team, Prairie Harm Reduction opened Saskatchewan's first and only SCS in October 2020. They are also currently the only site in the country with an exemption for indoor inhalation,

after a SCS in Alberta lost their funding. This means clients are allowed to smoke their drugs at the site, as well as inject or snort them.

Prairie Harm Reduction's site was designed for people who use crystal methamphetamine (crystal meth), which—along with HIV—disproportionately affects the local Indigenous communities. To accommodate these clients, special ventilation systems were built to allow them to smoke their drugs.

Prairie Harm Reduction also built the site to be sustainable by applying for a federal exemption that can be renewed. For Mercredi, this lengthy process was worth the wait. "How often do you get to open the first safe consumption site in a province?" he says.

Mercredi, a teacher by trade, has a big heart for people who use drugs. He explains that stigma and discrimination are so widespread, people are grateful to just be treated normally. "If you treat people who use drugs like a human being," he says, "you make a friend for life." His aim was to build a space that is first and foremost a community centre: "We have the only public washroom in the neighborhood, the only place you can get coffee and the only place you can use the telephone," he says. By creating

# Getting Started

**How does a supervised consumption site (SCS) get up and running? **Matt Bonn** hears the stories behind Prairie Harm Reduction (Saskatoon) and Dr. Peter Centre (Vancouver).**

a comfortable and safe environment, Prairie Harm Reduction normalizes and destigmatizes drug use for its clients. This empowers them to access the healthcare and social services they need to survive.

#### **THE STORY OF DR. PETER CENTRE**

Patrick McDougall is the director of knowledge translation and evaluation at Dr. Peter Centre, an HIV facility with a SCS in Vancouver's West End (pictured). As one of the first two SCS in Canada, their start was more ad hoc than Prairie Harm Reduction's. McDougall explains that when they started supervising injections in 2002, they didn't have a formal exemption. Instead, Dr. Peter Centre found a way to open without one. "We consulted with the Registered Nurses Association of British Columbia, who said that service was within the scope of nursing practice," he says. In 2003 they were granted a federal exemption along with Insite, another SCS in Vancouver.

Problems came when it was time to renew their exemption in 2006. Dr. Peter Centre learned that the signature of the then-federal minister of health wasn't attached to their original exemption. When the Conservative government's new minister of health found this error, he rejected their



application. Despite this, McDougall says they kept providing supervised injection services under the “nursing practice clarification” they had used before. In 2014 they applied for an exemption again, and after a change to a Liberal government in 2016, their application was approved.

Dr. Peter Centre is a member-only facility for people living with HIV, which is one of the biggest ways they differ from Prairie Harm Reduction. They have over 400 clients who have access to a health team offering HIV care, injectable opioid agonist therapy and prescription opioids (a harm

reduction measure known as “safe supply”). The centre also provides two meals a day, showers and a specialized nursing care residence. This approach treats food and housing security as an essential part of harm reduction.

The drugs consumed in each space also vary. While Prairie Harm Reduction focuses on crystal meth, Dr. Peter Centre is geared toward people who inject opioid drugs. Clem Fong, the centre’s knowledge translation clinical counsellor, explains that decisions about the target client base are important. “Every safe consumption site should be unique,” he says. “I think it should appeal to the culture of the group of users you are looking to serve.” As part of his work, he builds relationships with clients through the injection process itself. He guides members into the room, where they are then supervised by a nurse. “A couple of folks prefer to have me there,” he explains, “because we have an ongoing counselling relationship. That being said, the relationship was built in the injection room.”

As a long-running SCS with a knowledge translation team, Dr. Peter Centre has helped shift drug policy throughout Canada. Their research has produced models for harm reduction elsewhere, and they provide support for SCS and OPS workers across the country. This allows organizations like Prairie Harm Reduction to adapt the Centre’s approach to their local needs.

At the time of writing there are 39 legal SCS in British Columbia, Ontario, Quebec and Saskatchewan (with an application pending in Manitoba). Beyond this, many harm reduction activists have used short-term exemptions to set up OPS in places like the Atlantic provinces, where services don’t exist. In the context of COVID-19, these are especially urgent. Thanks to the hard work of organizations like Dr. Peter Centre and Prairie Harm Reduction, activists across the country have a blueprint for saving lives. ✚

Matthew Bonn is a freelance journalist and active drug user who specializes in drug policy, safe supply, and harm reduction.

## GLOSSARY

### Safe consumption sites or supervised consumption sites (SCS)

SCS offer spaces for people to legally and safely use drugs with staff trained to prevent overdoses. They offer new drug equipment to reduce the risk of HIV and hepatitis C. SCS also provide other harm reduction services like drug-checking, counselling and primary care. SCS receive long-term exemptions to operate from the federal government.

### Overdose prevention site (OPS)

OPS are spaces for people to legally and safely use drugs with staff trained to prevent overdoses. They offer new drug equipment to reduce the risk of HIV and hepatitis C. OPS receive shorter exemptions to operate from regional governments in response to urgent community needs.

### Opioid agonist therapy (OAT) or opioid substitution therapy (OST)

OAT or OST is a treatment for opioid use disorder where long-acting opioid medication is prescribed to manage withdrawal symptoms and drug cravings. It can help reduce harms and provide stability through structured, regular access to opioid medication.

### Safe supply

Safe supply is when pharmaceutical-grade opioids are prescribed as an alternative to the illicit drug supply. Illicit opioids are contaminated with unknown, potent substances that put users at risk of overdose. These include fentanyl, which can cause overdose for non-fentanyl users.









# Party Time

**Party n' Play (PnP) is on the rise in Canada. But how can we make things safer for guys who use drugs during sex?**  
**David Soomarie** looks at this new approach to harm reduction.

ILLUSTRATIONS BY FIONA SMYTH

**A**s Canada grapples with an opioid overdose crisis, harm reduction workers have stepped in to reduce the risks and harms of drug use. Supervised consumption sites (SCS) and overdose prevention sites (OPS) across the country now offer new injecting equipment, naloxone to reverse an opioid overdose, and referrals to treatment. Sites like Prairie Harm Reduction in Saskatoon (page 6) also have inhalation rooms for people who smoke drugs such as crystal methamphetamine (crystal meth), and calming spaces where clients can relax. But these services only work for people who choose to use them. In Canada, more and more gay, bisexual and men who have sex with men (gbMSM) are using drugs like crystal meth before or during sex. With this phenomenon, known as party n' play (PnP), harm reduction needs a different approach.

## What is PnP?

PnP can have different meanings, but it usually refers to two or more people—mainly gbMSM—who meet to take drugs (“party”) and have sex (“play”). Drugs are used in these settings to enhance the sexual experience. These are mostly crystal meth, gamma-hydroxybutyrate (GHB), cocaine and ketamine. Parties are often held at people’s homes and organized through hook-up apps or personal networks. Unsanctioned parties can also be held at sex clubs and bathhouses, although venues discourage this. The privacy of these events can help men who are not “out” or comfortable at gay bars to connect with others. Using drugs during sex can also override someone’s feelings of shame and anxiety, helping them to explore their sexuality and feel accepted. Crystal meth can heighten feelings of

confidence and euphoria, but this is followed by an abrupt comedown when effects wear off. As a result, some people may keep using over multiple days.

Since the 1980s, harm reduction for people who use drugs has focused on tools like clean needles and drug equipment. This has been successful at reducing HIV and hepatitis C transmission. Early HIV activists also applied the harm reduction approach to sex by sharing the message that condoms can prevent transmission of the virus. As the HIV epidemic has continued, these messages have evolved: for example, we now know that effective treatment means you can't pass HIV on during sex ("U=U"). However, harm reduction approaches often treat people who use drugs and gbMSM as separate groups. When it comes to PnP, some community members have developed their own tools to bridge this gap.

**"Queer sex is not often talked about. While you're living in a heterosexual community, PnP allows you to have the sex you want without shame."**

### Managing risks

Colin Johnson is a Black, gay, long-term HIV survivor from Toronto. As a community activist and passionate advocate for harm reduction, he hosts his own PnP events planned around harm reduction principles. To reduce the risk of HIV and hepatitis C, he gives his guests clean pipes and syringes, containers for used needles, and plenty of condoms and lube. He also stocks his home with water, fruits and snacks. And to reduce the risk of overdose, he keeps naloxone on hand and tests his drugs before each event. "There is shame associated with queer sex, which is driven by homophobia," Johnson says. This shame can be magnified by racism and stigma around HIV. To combat this, Johnson tries to create a relaxed, welcoming space at his parties. He makes sure that people can decide what they are comfortable with, and that nobody feels judged if they are living with HIV.

Akia Munga, another community activist from Toronto, also notes that shame is a driving factor for guys who party. "Queer sex is not often talked about," he says. "While you're living in a heterosexual community, PnP allows you to have the sex you want without shame." Parties can provide a way to escape these feelings. They create an overwhelming

sense of connection to others, partly from the drugs themselves but also from the context they are used in. In this sense, Munga explains, drug use serves a purpose. But the intensity of this experience can create problems when people return to their normal lives. Feelings of rejection and isolation can be heightened after a party is over, prompting some guys to use drugs again.

While the drugs used for PnP can be enjoyable, they also carry some risks. Dr. Michael Fanous, a pharmacist in Toronto, explains that these can vary depending on which drugs a person uses, their physical and mental health, and any medicines or supplements they are taking. "Many drugs are taken by people who PnP," Dr. Fanous says, "but the biggest risks come with crystal meth. These range from heart complications and sleep problems to mental health issues like depression, anxiety and psychosis." They

also say that GHB "can cause something we call cardiorespiratory depression, where your heart rate and breathing become dangerously slow." Both GHB and crystal meth carry a risk of overdose, which can be fatal. This is common with GHB, because doses are small and hard to measure precisely—especially if you're already high.

Dr. Fanous explains that "prescription medicines like HIV treatment or antidepressants can also change the effect of drugs on your body, making overdose more likely. Injecting or 'slamming' drugs also increases this risk." When these drugs are mixed with sex, someone may be less able to consent or might make choices they normally wouldn't. Dr. Fanous says, "It's important for anyone who is thinking of PnP to stay in touch with your healthcare team. Harm reduction counselling and accountability partners—people who can help you keep on top of your drug use—are also great tools."

While there are risks with using any drug, not all drug use is problematic. The Canadian Mental Health Association (CMHA) outlines a spectrum of drug use. This ranges from casual or non-problematic use to problematic use and, finally, chronic dependence. For some guys, PnP can be a manageable part of their sex life. But for others, PnP can have serious effects. The CMHA says drug use is problematic when it has severe negative consequences on someone's personal life, family, friends and community. Chronic dependence is when someone can't stop using despite these effects. This can lead to the loss of jobs and housing, which may then lead to survival sex (where someone has sex to meet their basic needs for food and shelter). When someone regularly uses drugs during sex, this can affect their relationship with sex and intimacy in the long term.

For people living with HIV, there are some extra risks to be aware of with PnP. Using drugs for long periods can make someone forget to take their medication, which could cause





## HARM REDUCTION TIPS

- ◆ Plan for your safety. Think ahead of time about your limits. Are you taking risks with people you trust? How much will you use, how long will you use and what method (e.g., smoking or injecting) are you comfortable with?
- ◆ Find a therapist or friend outside of the PnP scene you can have honest conversations with.
- ◆ Start low, go slow. Give your drugs time to work before taking another dose.
- ◆ Know where your supplies are coming from.
- ◆ If you are using fentanyl strips, be cautious as these test only a small amount. If the test is negative, it doesn't always mean that there is no fentanyl in your drugs.
- ◆ Consider getting naloxone training.
- ◆ Make sure to take care of your body. Give yourself food, water and time to sleep.
- ◆ Get regular sexual health checkups.
- ◆ Ask yourself if PnP is meeting your needs. The reasons people use drugs can change; if it stops being enjoyable, take time to reflect on this.
- ◆ Know the Good Samaritan law. If you call the police to report an overdose, you shouldn't be charged for drug possession.
- ◆ Tell a friend where you are going.
- ◆ Set a timer so you don't forget to take your HIV medications. Speak to your doctor or pharmacist about any recreational drugs you are taking, so they can advise you about interactions.
- ◆ If you want to reduce or stop your use, take an inventory of how much you are using. This can help you decide how to reduce it and understand your triggers.
- ◆ For information on support groups or counselling, contact your local LGBTQ+ organization.

directly to their clients. For instance, MAX in Ottawa offers a discreet online service for people to customize and order their harm reduction supplies, which can be picked up or delivered. They also conduct outreach at gay bars to share harm reduction tips with local guys. For all these examples, being culturally relevant and responsive are more successful than a “one size fits all” approach. Ultimately, they rely on confidentiality, trust and a non-judgmental approach to clients.

Among the experts who spoke to CATIE, all said that people who use drugs should play a critical role in delivering these services. Ryan Tran at ACAS explains that “people who use drugs know more, are less likely to be judgmental and usually have good intentions of wanting to help others.” Maticus Adams from MAX also says that people who use drugs can “develop programs for people who PnP, identify gaps and clarify messaging ensuring cultural competence.” At ACCKWA, for example, people who PnP play a key role in training other members of staff. Across the board, service providers agreed that people who use drugs and work in the sector should be fully supported. They said that these peer workers should also be involved in debriefing sessions after training workshops and given access to counselling support if needed. They also said that adequate pay for peer workers is a form of harm reduction.

While there has been progress in building these tailored supports, some gaps remain. A major problem is access, since many services are only available in cities like Vancouver, Toronto or Montreal. These services often only address certain needs, like harm reduction supplies. To improve this, service providers who spoke to CATIE suggested a more integrated approach. Ideally, services should explore the connection between the mental health challenges that queer men face—such as the trauma of homophobia, transphobia and racism—and their relationship to drug use. Tim Guimond, a queer psychiatrist, explains that PnP can appeal to people struggling with their mental health. “There are people who feel they are on the margins,” he says, “and PnP is a way for them to feel better and be accepted.” To address this, he says, it's important to build community connections. He argues that ideal services would be client centred and holistic. These would include drug counselling and psychotherapy to help people manage their health.

Community activists Johnson and Munga also emphasize the need for open conversations about PnP among LGBTQ+ organizations. They suggest that service providers need staff training, more psychologists, harm reduction specialists and greater funding for culturally relevant programming. And although some organizations are starting to respond, more work is needed to combat stigma by agencies, activists and people who use drugs. Only then will guys who PnP have the information, skills and tools to do so safely. +

David DK Soomarie is an openly queer HIV-positive advocate who works with LGBTQ+ and HIV-positive communities in Toronto.





# SEX IN A PANDEMIC

What do we need to know  
about sex and COVID-19?

**Amanda Giacomazzo**  
breaks it down.

**D**uring the COVID-19 pandemic, public health guidelines tell us to keep physical distance between ourselves and others. This is because SARS-CoV-2 (the virus that causes COVID-19) is spread through contact between people and sometimes through touching your face after touching surfaces with the virus on them. Other guidelines include wearing new or clean face coverings, washing your hands often, and limiting contact with those outside of your household or small social circle (a “bubble”), especially in indoor spaces. So, what does this mean for your sex life?

The safest sex avoids in-person contact. This could be masturbating, sexting, or video and phone sex. But since in-person sex can help your health and well-being, these solo options aren't always realistic. Limiting sex partners to those in your household is the next safest option, followed by limiting your partners to a small social circle.

It's important to talk to your sex partners about COVID-19. Where possible, you should have an open conversation about if they are following public health guidelines and if they have any symptoms. If you or your partner is feeling unwell or might have been exposed to someone with COVID-19, you should avoid in-person sex.

Since those without symptoms can pass the virus, asking a sexual partner if they are feeling ill may not be enough. To reduce your risk, you could avoid kissing or sexual positions with close face-to-face contact, or even wear a face mask during sex. However, we don't currently know the effectiveness of these strategies in the context of sex.

If you are having sex during the COVID-19 pandemic, don't forget to take care of your sexual health. It's a good idea to have regular tests for sexually transmitted infections (STIs) especially if you have new or multiple partners (although access to testing may vary during this time). By taking your HIV treatment and staying in touch with your doctor, you can also keep your viral load at an undetectable level, which means you can't transmit HIV during sex. If you have a detectable viral load, your partners can take pre-exposure prophylaxis (PrEP) or you can use condoms to prevent HIV. Condoms will also prevent other STIs. +

The information in this article was based on currently available research at the time of printing related to the transmission and prevention of COVID-19.

Amanda Giacomazzo is CATIE's manager of community programming.





# The Parent Trap

An increasing number of people living with HIV want to become parents. In the age of “Undetectable = Untransmittable” (U=U), why are they still facing stigma and discrimination?

BY ALEXANDRA KIMBALL

ILLUSTRATIONS BY KATY DOCKRILL

## MG

Raposo\*, 50, always wanted to be a dad. Before immigrating from South America to Toronto in 1980, he grew up in a bustling household. “I’m the baby in a big family of 12,” he says. “My house was a neighbourhood hangout. I love children.” As a gay man living with HIV, though, he had thought parenthood was “unrealistic.” It wasn’t until he was in his 40s that he reconsidered his dream of being a father. He was in good health with a stable job and a solid social network. He felt ready. “I was done living *la vida loca*,” he laughs. “My ex-roommates had adopted a little girl and I started asking them questions about adoption.” He researched the Children’s Aid Societies (CAS), which are government-approved agencies providing foster care and adoption for Canadian children. Through CAS, adoption is possible even if a parent is single, gay, or living with HIV.

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\* Raposo, like the other people living with HIV in this story, has asked that we use a pseudonym.

At first, things went smoothly. “I had a great social worker,” Raposo says. As part of the process, the social worker conducted a home study. They assessed Raposo’s parenting abilities by interviewing him, his friends and family members. They also made home visits to confirm his residence was safe for children, and they reviewed his

As people  
with HIV live  
longer, healthier  
lives, more  
are interested  
in becoming  
parents.

finances. Raposo passed the home study and a criminal background check, but he hit a roadblock when he asked his doctor to confirm he was healthy. “He said, ‘I’d approve you to adopt a dog,’ but it wasn’t fair for me to bring up a child if I had a shorter lifespan,” Raposo remembers. “I felt like the ground disappeared under my feet.”

A month later, Raposo was in the emergency room for an unrelated incident. An HIV specialist happened to be on duty, and they started talking. Raposo mentioned that his doctor had refused to write a letter, and she told him that was wrong. “She said, ‘Why not?’ She wrote me a letter and gave it to my social worker,” says Raposo. With the letter, he was approved for adoption. Two years later his son, Terrance, was placed with him at 18 months old. By adoption standards, this was very quick. “It’s the best thing I’ve done, being a dad,” he says. While single fatherhood can be challenging, he has a strong support network. “He’s with me all the time,” Raposo beams. “My friends know, if we go to dinner, my child is coming along.”

## Barriers to care

Since 1996, people living with HIV have been protected from discrimination under the *Canadian Human Rights Act*. Despite this, stigma persists. Canadians living with HIV still face social and political barriers. For example, people who do not disclose their HIV status to their sex partners in certain contexts can face criminal charges. Family building is another area where people living with HIV can be marginalized. Many experts agree that as people with HIV live longer, healthier lives, more of them are interested in becoming parents. This includes gay and bisexual men who may not be aware of their options. In 1995, CAS approved gay and bisexual men for fostering and adoption. Since then, adoption has been a common form of family building for gay couples and single gay and bisexual men. However, a 2018 study of HIV-positive gay and bisexual men in the UK found that while over half wanted to become fathers, their healthcare providers “rarely” talked about parenting options.

The reality for people living with HIV, no matter their gender or sexual orientation, can be very complex. In 2014, researchers in the Women and HIV Research Program at Women’s College Hospital surveyed 75 Canadian adoption service providers. They assessed any barriers HIV-positive people might face. While 64 percent said that people with HIV could adopt with them, 23 percent weren’t sure.

The study also found that some forms of adoption had more barriers than others. For example, HIV-positive people could not apply for any international adoptions because of policies in the host countries. In Canada, private adoptions—which arrange adoption directly between a Canadian birth family and the prospective parent(s)—were also difficult. This is because an applicant’s health history is shared with birth families. This means that these families could discriminate against people living with HIV. The study found that public adoptions through CAS, like Raposo’s, were the most accessible to HIV-positive people. However, when researchers did a follow-up study of people’s experiences through the adoption process, they found that obstacles remained. These came from social workers, family doctors, and administrators who may lack knowledge around HIV.

“There is a lack of knowledge and awareness about HIV among service providers,” says Angela Underhill, PhD candidate and co-author of the study. “Somebody who was really worried about the process may call an agency to find out if they are eligible and be told ‘I don’t know’.” This could discourage them from trying other providers,” she explains. Uninformed doctors, like Raposo’s, may refuse to give medical clearance for an applicant. And for people trying to adopt outside their specific region, their health information is shared even if they’ve already been approved in their home province. “There were extra challenges throughout the process, and opportunities for bias and discrimination,” Underhill says.



Regardless of their gender, many HIV-positive people may want to have biological children. The good news is that people living with HIV can safely become pregnant if they are on effective treatment. If they have an undetectable viral load before pregnancy and maintain this throughout, there is no risk of transmitting HIV to their baby through pregnancy or childbirth. Dr. Deborah J. Money, professor of obstetrics and gynecology at the University of British Columbia, recommends seeing a doctor before trying to conceive. “This is to see if there are any challenges with your HIV,” she says. For example, someone’s HIV medication and viral load may need to be reviewed. “Secondly, there are other steps to pregnancy planning that affect everyone. These can be simple things like taking folic acid before conception, or more complex issues like older age, high blood

Canada has been  
a hub for people  
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children through  
gestational  
surrogacy.

pressure, obesity, and smoking.” For trans people living with HIV, biological parenting is also possible with effective treatment. But Money points out that “the overall barrier is getting the right expert advice.” Trans people face high poverty rates because of stigma and discrimination, and it can be hard to find experts on both trans health and HIV.

### Surrogacy in Canada

Surrogacy is an alternative parenting option for people living with HIV, but it can present its own challenges. Lawrence Cutler and Jethro Green are a Toronto couple who have been together for 12 years. In 2015, they decided to expand their family. “I grew up in a large family, so home always

included children for me,” explains Cutler, who was diagnosed with HIV in 2010. “Initially we thought of adoption,” he says, “but we were told that the only children available to adopt had developmental disabilities. That wouldn’t have been fair since we are older and couldn’t care for the child indefinitely.” The couple could have been foster parents, but they had concerns. They knew that Canada has a policy of family reunification. This is where each province tries to reunite foster children with their birth family before placing them for adoption. Cutler worried that “we could bond with a child and then see it go back home.” Like a growing number of gay couples worldwide, they decided to try surrogacy.

Since the mid-2000s, Canada has been a hub for people who want to have biological children through gestational surrogacy. This is where someone outside the immediate family carries a pregnancy for people who want to become parents, using an embryo made outside the body. In this process, known as in vitro fertilization (IVF), an egg is fertilized with sperm in a lab and then put back into a uterus. Canada also allows same-sex couples and single people to work with surrogates, and the process is more affordable than in other countries. This is because sperm or egg donors and surrogates can only be reimbursed for costs directly related to the surrogacy process.

Cutler and Green live in Ontario, where provincial insurance funds one IVF cycle per person. But because Green was not an Ontario citizen, he was not eligible for funded treatment. As a result, the couple used Cutler’s sperm. They didn’t expect any problems, because his viral load was undetectable. But after creating five embryos using eggs from a local donor, they struggled to find a surrogate. They signed with two different agencies who promised to find them a match, but the pair kept hitting roadblocks. Normally, the process takes a few months to a year, but the pair spent four years trying with no success.

The couple paid \$15,000 total in “matching fees” upfront. They knew that once an agency provided them a match, they could not get a refund. “We matched with a few surrogates,” Cutler says, “but they had fertility problems. They wouldn’t have met the clinic recommendations.” The agencies knew of Cutler’s HIV status, and he wasn’t sure if it factored into the matching process. Were the agencies not passing their profile to surrogates because he was living with HIV? Or were surrogates rejecting their profile once they saw his status? Were the surrogates even informed about U=U? “We were getting frustrated and suspicious it had something to do with my status,” Cutler explains. “Were we being strung along?”

In 2019 the couple matched with a surrogate on their own through a Facebook group. But they found that Cutler’s HIV status kept coming up in ways that troubled them. “Our doctor had to tell the surrogate of my HIV status, which was a little strange because I’m undetectable,” he explains. The couple were especially worried about this disclosure





when the surrogacy failed. “It’s a violation of privacy that is completely unnecessary,” he says. “These people aren’t in our lives, but now they have this stigmatizing information.”

## Changing regulations

Sperm and eggs from people with an undetectable viral load have been approved for IVF since 2013. Because surrogacy uses IVF, they are also approved for this process. Despite this, there is still a lack of knowledge around U=U in the surrogacy industry. This means intended parents like Cutler are at a disadvantage. Surrogacy agencies report that more people living with HIV want to have babies via surrogacy, but this knowledge gap still creates barriers.

“Our clients include a number of intended parents where one or both partners live with HIV,” says Lindsay Ambeault from JA Surrogacy Consulting in Calgary, Alberta. Her agency has worked with surrogates who carried babies for people living with HIV. In her work, though, “one issue we’ve run into consistently is the lack of good-quality research on HIV and surrogacy.” Materials do exist, she says, but they tend to be from the United States. This means clinic recommendations may be different. As a result, she says U=U is “an unheard-of concept in the surrogacy world.” Well-meaning surrogates may refuse a person living with HIV simply because they don’t know the current science.

The policies of fertility clinics can also affect intended parents living with HIV. Surrogacy in Canada is governed by the *Assisted Human Reproduction Act*. Until recently, this law was vague about how clinics should store and treat sperm from people living with HIV. As a result, many clinics thought they were unequipped to serve HIV-positive people. New regulations to the *Assisted Human Reproduction Act* were introduced in 2020: the Safety of Sperm and Ova Regulations. These clarified the use of semen from people living with HIV in IVF as well as sperm donation. “People living with HIV can donate sperm now and there’s a general consensus that reproduction is safe for them,” says Sara Cohen, a reproductive lawyer in Toronto. “However, doctors are still required to tell surrogates that the embryo they will carry has been created with HIV-positive sperm,” she says.

These regulations have raised questions among HIV experts and fertility doctors. They say that the new regulations don’t distinguish between detectable and undetectable viral loads in semen. As Cutler explained, forcing doctors to tell surrogates about someone’s HIV status is discriminatory. Also, many doctors don’t know how to apply the new regulations to surrogacy. Tom Hannam is a reproductive endocrinologist and director of Hannam Fertility Centre in Toronto, which serves a large LGBTQ population. He says that surrogacy for people living with HIV under the new regulations is “much more difficult.” “This was never

the intent,” he says. “It was supposed to make surrogacy more accessible and make it easier for people to work with known donors.” The new regulations were also rolled out at the start of the COVID-19 pandemic, which slowed down fertility services overall. “The challenge is matching the medical system to the legal system,” he explains.

The slow, complicated pace of progress for future parents living with HIV is frustrating for experts. But the burden of this is carried by the people who long to have children. In Cutler and Green’s case, it was too little, too late. After their failed surrogacy attempt in 2019, the couple decided to call off their journey. They donated their remaining embryos to their fertility clinic for research, which Cutler describes

“The challenge is matching the medical system to the legal system.”

as deeply painful. “The sad part is someone had donated a lot of baby equipment to us,” he tells me. It’s one of many setbacks he’s faced as a man living with HIV, even in a country known for its progressive medical system. “Living with HIV made me appreciate the painful effects of stigma, even when science says I am not a threat to anyone,” he says. “I was not prepared for this stigma to still exist in the surrogacy world.”

For Raposo, the challenges he faced have made him more aware of how insidious the effects of stigma are—and more determined to keep fighting them. “From that experience, I always tell my son to go after his dreams and never let anyone tell him otherwise,” he says. He is also encouraging to other people living with HIV who want to become parents. “HIV doesn’t make who you are and never let anyone tell you the contrary,” he says. “You deserve and have the right to be a parent like everyone else.” +

Alexandra Kimball is a journalist and non-fiction writer based in Toronto. Her first book, *The Seed: Infertility Is a Feminist Issue*, was published in 2019 by Coach House Books.





# My Generation

HIV activism has been going strong for almost 40 years.  
What can older and younger activists learn from each other?

**Darien Taylor** brings together a diverse group  
of HIV activists to talk about their work.

ILLUSTRATIONS BY AARON MCCONOMY

**T**oward the end of 2020, and in the midst of the COVID-19 pandemic, Darien Taylor sat down for a physically distanced Zoom interview with four people living with HIV to get their takes on the role of HIV activism: past, present and future.

**Could you introduce yourselves?**

**MULUBA HABANYAMA:** I was born with HIV. I've now been living with it for 27 years. When I was 21, I decided to rip the Band-Aid off, so to speak. I disclosed my HIV status publicly, and I've been doing activism ever since. I wear many hats, telling my story, speaking, and educating young people.





*“The vulnerabilities of certain communities, HIV criminalization, racism, discrimination, homophobia, lack of access to care: these issues are shameful.”*

**Muluba Habanyama**

**TIM McCASKELL:** I worked in the early gay movement in the '70s and was involved in *The Body Politic* and *Xtra!* magazine, and the Right to Privacy Committee, which defended people after the Toronto bath raids. I was a founding member of AIDS ACTION NOW! in 1987–88. I guess I'm a bit of a dinosaur.

**TREVOR STRATTON:** I work for the Canadian Aboriginal AIDS Network. I'm the coordinator of the International Indigenous Working Group on HIV & AIDS. I also am engaged with the 2-Spirited People of the 1<sup>st</sup> Nations, a community organization for two-spirited people in and around Toronto. I was diagnosed with HIV in 1990, 30 years ago. As I age, I see my role as a mentor.

**AIDAN DOLAN:** With regards to activism, I have to say I'm such a novice. I'm a baby activist. I'm here to talk about my experiences as someone who is recently diagnosed with HIV. I am an aspiring artist and I'd like to channel my identity into the work that I do.

#### **What is your definition of activism?**

**TIM:** The iconic AIDS activist group is ACT UP, and Toronto's AIDS ACTION NOW! was cut from that cloth. Activism in the '80s meant the involvement of people who were directly affected by HIV/AIDS. Both ACT UP and AIDS ACTION NOW! were volunteer organizations without paid staff. We didn't receive money from pharmaceutical companies or government because those were the people we had to bark at.

Nowadays the word “activism” seems to be used in a much wider sense. But at AIDS ACTION NOW! we always distinguished between activism and service provision. For example, we did a lot of work around treatment information in the early days. But when we realized that the task of providing treatment information was so huge that it required a service organization, AIDS ACTION NOW! created the organization that eventually became CATIE. We didn't try to do it ourselves because we didn't have the capacity. I don't know how useful it is to make that distinction between activism and services, but it was certainly one that we made in the old days.

**AIDAN:** To me, activism is anything that works towards a purpose. So, I think HIV services are totally a part of activism. My involvement in Positive Youth Outreach at the AIDS Committee of Toronto is what got me interested in this interview. HIV services build community directly. As someone interested in art, I think a lot about General Idea, and the AIDS quilt, and Keith Haring. That art-based activism became part of queer culture.

**MULUBA:** Activism is taking a stand, fighting, and trying to be a part of the change. I think Tim's distinction between activism and service provision is very



*“The real challenge that faces activism these days is to work together as a community when we’re no longer all in the same boat.”*

**Tim McCaskell**

interesting. A little pot of money to tell our story is sometimes appropriate. But then there are protests that you go to because you want to. I don’t think activism is always doing the actual work. For example, during the recent Black Lives Matter protest in Toronto, a white friend who has lots of experience organizing protests made sure there was enough security there. Being an ally is important, too.

**TREVOR:** My thoughts around activism have evolved. I remember right after I was diagnosed, two big First Nations guys came up to me in one of the gay bars and said, “Welcome to the family. Have you heard about 2-Spirited People of the 1<sup>st</sup> Nations? We are reclaiming our traditional roles. We have thousands of years of history.” I was blown away by the psychic energy of their activism, even though I wasn’t ready to join them yet. After my HIV developed into AIDS, I finally started feeling like I was an activist, and I started travelling to different First Nations to share my story. There were people in those communities living with HIV who didn’t want to disclose. It was too dangerous for them. But they would set up the chairs for the meeting, or they’d be cooking in the back. And that is activism to me.

It’s different now that HIV is a manageable illness. What motivates an activist now that there is no sense of desperation? And what does activism mean with COVID? But lastly I want to say this: there are different layers of activism. Most service providers are activists. They’re trying to keep government and institutions in check. Then there are people within government and the private sector working within the system to generate change. And then there are independent activists who keep us all in line.

**What changes have you seen in activism over the years?**

**MULUBA:** I was born in 1993 and diagnosed in 1995. There were a few medications at the time. They weren’t the greatest, but I acknowledge that they were available to me because of the work of activists. I’m thankful for that. Because of how far we’ve come since those days, activism looks a little different. People with HIV are living long lives. We’re able to get a PhD ourselves, and sit at the table as equals with the experts. That’s amazing. But sometimes we have to use the old methods. We have to be rowdy and loud. The vulnerabilities of certain communities, HIV criminalization, racism, discrimination, homophobia, lack of access to care: these issues are shameful. As I get older, the activist passion is rising in me. We have to find our talents and use them in this fight.

**AIDAN:** Maybe I can talk about what I know about activism and access to services. The Toronto AIDS Memorial has an Instagram page that posts stories memorializing



*“Most of my work is international and I’m like, ‘Why the hell can’t we get HIV medication for everybody on the planet?’”*

**Trevor Stratton**

loved ones that folks have lost to AIDS. It is a great way for people my age to connect to the history of HIV/AIDS activism and to hear stories from elders in our community on a platform we are actively engaging with. I visit it almost every day. It makes me feel less alone.

Personally, I had tremendous access to lots of different HIV services: counsellors, testing, mental health supports. But I still struggled so much, and I still became HIV-positive. It goes to show that the story isn’t over yet. Of course we all want to end AIDS, but there is something about young people who are continuing to be diagnosed with HIV that we need to discuss further. I’m grateful for all the hard work of past generations to build this network of services because HIV doesn’t feel like a death sentence. I don’t think it’s easy, but I have hope.

**TIM:** Activism has changed a lot because society has changed a lot. In the ‘80s, when AIDS ACTION NOW! started, our society was much less disparate. The gap between rich and poor was not nearly as great as it is today. The gap around marginalization and poverty has become racialized, and so that throws anti-Black and anti-Indigenous racism into the current mix. When we were all in the same boat, it was relatively easy to say, “OK, this is an issue that affects all of us.” But as society pulls itself apart, and some of us get services and others don’t, suddenly we’re in different boats. We’re fragmented.

And the other thing is that the level of risk people are asked to embrace if they’re going to be an activist has changed. If you look back at those early days of AIDS ACTION NOW!, most of the members were white, relatively educated gay men. So, even though all this horrible shit was happening to us, we had a certain level of privilege that allowed us to barge into a government office and lock ourselves to the furniture. If you were an undocumented person and you did that, you’d be deported. The level of risk is really, really different for people. To me, the real challenge that faces activism these days is to work together as a community when we’re no longer all in the same boat.

**TREVOR:** People who are already disadvantaged, people who are not in control of the health policies and legal frameworks in which they live, seem to be much more vulnerable to HIV. It’s someone else’s system: it wasn’t really created for Indigenous people. It wasn’t really created for African, Caribbean, or Black people. This system is very risky for us.

If I feel strong and enfranchised, why should I be an activist? Why should I disclose my HIV status to anybody? Why not just take my pills, and go to work, and get my degree, and buy my big house? Why should anybody even need to know I have HIV? The burden of activism has shifted to populations and people who are not privileged, which makes it difficult. When privileged people are activists, more doors open for all of us.





*“Hit the pavement,  
get out there, talk to  
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collective effort to  
address HIV.”*

**Aidan Dolan**

**What are the issues that currently need an activist response to move them ahead?**

**MULUBA:** For people born with HIV, the transition from the children’s clinics where everybody does everything for you to the system of health care for adults could be improved. I know it’s nice to be taken care of, but there are some things that the young people who grew up in the protective environment of CHEO [Children’s Hospital of Eastern Ontario] in Ottawa and SickKids in Toronto don’t learn, that they need to know about as adults.

**TIM:** We know that a major driver of HIV infection is crystal meth use. Yet I still hear fuck-all from AIDS service organizations. Everybody sits on their thumbs because they’re so afraid to talk about drug use. A clear warning to people is needed: “Don’t go there. Meth is a bad one.” Crystal meth use is a pretty concrete issue where a lot more could be done and it’s not going to come from institutions. It’s going to require some grass-roots activism by people who’ve managed to come out on the other side of it.

**AIDAN:** And there is another side. I came out of it. I’m eight months sober off of crystal meth, and I was diagnosed with HIV while I was using. It was difficult. I blame my diagnosis on crystal meth. So hit the pavement, get out there, talk to your friends, talk to your family, because there needs to be a collective effort to address HIV.

**TREVOR:** Most of my work is international and I’m like, “Why the hell can’t we get HIV medication for everybody on the planet?” The prices for medication, the lack of distribution networks, and the absence of political will to save lives—it’s apartheid. This situation is completely unacceptable for me. And it doesn’t bode well for COVID vaccines either. The criminalization of HIV—and I’m not just talking about the criminalization of HIV non-disclosure—I’m talking about the criminalization of same sex relationships, of sex work, the criminalization of simply being transgender, the criminalization of drugs. It’s killing people. We should all be ashamed. I can’t say it any more plainly than that. +

Darien Taylor has been living with and working in HIV for the past thirty-plus years.

Trevor Stratton is a citizen of the Mississaugas of the Credit First Nation and works for the Canadian Aboriginal AIDS Network (CAAN).

Tim McCaskell is a gay activist dinosaur and a founding member of AIDS ACTION NOW!.

Muluba Habanyama is a human rights activist and communications specialist who has been living with HIV since birth.

Aidan Dolan is a queer non-binary artist and baby activist living in Tkaronto/Toronto.



## CATIE at 30

As CATIE turns 30, three employees reflect on their time at the organization and how it has evolved over the years.

INTERVIEWS BY RONNILYN PUSTIL

### DARIEN TAYLOR

Time at CATIE: 1991 to 1993 (board member), 2004 to 2012 (employee)  
Position: Director of program delivery

My history with CATIE started in 1989 with AIDS ACTION NOW!—the activist organization in Toronto that created the idea of CATIE and got it off the ground. One of our early initiatives was the Treatment Information Exchange (TIE) project, which was national and included a phone-line component. CATIE originally stood for Community AIDS Treatment Information Exchange. When it became a national organization with government funding in 2000, it became the Canadian AIDS Treatment Information Exchange.

I've always been attracted to the idea of knowledge exchange. When I found out I was HIV positive in 1987, I started reading booklets from the United States that were filled with research data in plain language for people with HIV. It was incredibly reassuring to have that knowledge at a time when there was so little that you could do for yourself. Putting scientific information into simple language so people with HIV could participate in these conversations was important to me. At CATIE I was able to do this full-time.

As CATIE's director of program delivery, I worked with the educators to deliver workshops and information to people with HIV. In the course of my



*"I've always been attracted to the idea of knowledge exchange."*

job, CATIE began to focus on service providers, so we shifted a lot of our knowledge translation work towards them. I had about five staff in my department, and during that time I was able to streamline the "syllabus" that they delivered. I also worked on *Managing Your Health*, which was our comprehensive resource for people living with HIV.

Seeing through the revisions to *Managing Your Health* was one of my biggest accomplishments at CATIE. Working on that was very difficult.

We fell behind on it and lost our editor, so I felt an enormous amount of relief when it was finally completed. I remember back in the day at AIDS ACTION NOW! we were working on what we believed would be a pamphlet for people with HIV and AIDS, and that eventually became *Managing Your Health*. There's something important about it—it's so substantial and is so tied in with the beginning of CATIE.

My own health has always been good. I was able to last a long time without treatment. I started taking meds in 1996, then stopped four years later because of side effects. I went back on them in 2004. At CATIE I was the only director with HIV, and sometimes it was hard being a woman and a person with HIV. In 2012, I started to get impatient with the science of U=U [undetectable = untransmissible] and was feeling constrained at work. People were so cautious about saying that treatment could prevent transmission. I thought, "I'm 55. Maybe now is a good time to acknowledge that in HIV years I'm actually 65, and just do my own thing around the house in my slippers with the cats." I've been retired for eight years now.

### RALPH WUSHKE

Time at CATIE: 1996 to 1999  
Position: Treatment information consultant (TIC)

My move to CATIE was really an escape from Saskatoon, where I had been the executive director of AIDS Saskatoon. From late 1994 to spring 1996 I was on long-term disability with HIV and I was incredibly depressed, more because of heartbreak than HIV. Out of this desperate unhappiness, I decided to move to Toronto. I got a job and moved there in June 1996.

At CATIE, I was a TIC—treatment information consultant. We were on the phones eight hours a day, five days a week. We got all kinds of callers asking about treatments, side effects, complementary therapies, and so on. Many people needed peer support and counselling, but we weren't trained as counsellors and we were forbidden to



*"I was the listening ear for people who were having a rough time."*

do it. Of course, we all did some of that. It was a balancing act.

I am a pastor and a theologian, and I try to live ethically. At CATIE, that was the other sort of role I had. In 1978 I was ordained as a Lutheran pastor, but I was kicked out of the ministry in the mid-1980s because I came out as gay. Despite this, I never left my faith, and everybody at CATIE knew that I was a Christian. Often people would slink around to my office and say, "Can I come in for some pastoral care?" I was the listening ear for people who were having a rough time.

When I started at CATIE, combination therapy was new and the clinical trials for AZT, 3TC, and indinavir were happening. Dr. Sharon Walmsley was running a clinical trial with that very combination, which saved my life. At the beginning, my T4 count was 14. I had some minor but stubborn infections, like molluscum contagiosum, a viral skin infection that had spread to my face. Within a year of taking treatment, my T4 count was in the 400s—well within a normal range. So, while I was at CATIE, I was tracking this improvement in my own health.

Personally, I got a lot out of working at CATIE. I had fled Saskatoon to save

my life because I was in deep emotional trouble there. When I was at CATIE I would work out at the Y and I always started out on the stair climber. Most days when I got on the stair climber I'd start crying as I thought about my life back in Saskatoon. By the end of my first six months at CATIE, I was on the stair climber and realized I wasn't crying anymore. I'll never forget that moment. Suddenly it was like, "Oh, the world is a different colour!" The abysmal greyness and sadness and weightiness was over. Life had begun again.

### SEAN HOSEIN

Time at CATIE: 1990 to present

Position: Science and medicine editor

Aside from being the science and medicine editor, I'm also one of the cofounders of CATIE, along with George Smith and Alan Cornwall. When we started CATIE in 1990, we were working together as part of the Treatment Information Exchange. People with HIV were being neglected simply because HIV was seen as a disease of gays and drug users, who were despised by the larger society (and still are to some degree). They were being neglected, so we decided to stand with HIV-positive people and try to help them through this terrible crisis.

One of the things we found out was that doctors were having a hard time keeping up with the latest information—it was changing so fast. So, there was a need to help both doctors and people with HIV find out more about the disease, prevent AIDS-related infections, and know that treatments were in the pipeline.

Before working at CATIE, I had been writing a column called *Treatment-Update* in community newsletters since 1985. This covered HIV and potential treatments. After we founded CATIE, I continued to do this and also sat on the board for the first two years. I still write *TU* today, but now I write about many more topics, and I also write *CATIE News* articles. Back in the early '90s, because very little was known about the virus, everything

was experimental. There was a sense of urgency, as people were getting very sick and dying. You didn't know who would be alive from one week to the next.

Now, thanks to treatment, many people with HIV will live into their senior years. Among people who know their status and who adhere to treatment, AIDS-related infections are rare. Back in the early '90s, the goal and focus for doctors and patients was about surviving the next life-threatening infection. Now it's about growing older. So, part of what I do is help people focus on aging well with HIV.

I think that in the next 10 years or so the virus will be brought under control. There might even be a vaccine, because right now, based on



*"Part of what I do is help people focus on aging well with HIV."*

studies in monkeys, we have the first vaccine that might reduce the risk of HIV transmission by 70 percent. I'm hopeful that the next generation of vaccines could aim for an 80 or 90 percent reduction. What I'm saying is, I think my job will become unnecessary 10, 15 years from now. My hope is that I'll be able to retire and live in an AIDS-free world. +





*Amețitor [Dizzying], 2019*

## Confession, Care & Community

Multimedia artist **Dee Stoicescu** talks to **Jessica Whitbread** about finding community and finding themselves.

**D**ee Stoicescu is a Romanian-born queer artist and writer from Toronto. Their art is a deeply personal and poetic account of their journey to reconnect with their Romanian ancestry and navigate deep family secrets. Dee's work engages queerness, HIV, immigration, and childhood; it tries to express their need for understanding from their family and their desire to find community.

**Jessica: Can you tell us a little more about yourself and your work?**

**Dee:** I like to think of myself as a creative human. Currently, I am the coordinator of a 2SLGBTQ+ youth centre. I really enjoy working with young folks. They have helped me to open up about my non-binary identity and become more comfortable exploring what that means as a queer person living with HIV.

*Queer Virus: Radical Sick Queer Softness and Romanian Diasporic Identity* (2019, pictured) is a digital photo series that was my entry point for reflecting on my illness in relation to society. It's my "the personal is political," if you will. This work features a lot of "firsts" for me and it's experimental in many ways. After my sister gave me a camera I played around with editing software to layer and pixelate images, and it was the first time I felt comfortable being public about my diagnosis.

Because the images are taken in a domestic space, the work is deeply intimate. I like to think that intimacy crosses time and space and is actually quite a public feeling. It's a way of connecting with my ancestors through everyday objects and settings and sharing that with the world.

**J: I'm very intrigued by your choice of overlapping images—together they have an eerie, abandoned, post-Soviet feel. Maybe this is the ancestors telling their secrets?**

I was pleasantly surprised at how "eerie" it ended up. I'm really interested in theories of "haunting" and being in touch with past histories. Thinking of histories as a haunting can remind us of things unsaid or left unfinished, whether on a personal, family, or community level.

The choice of overlapping images is a way of representing my complex experience of living with HIV. I'm also queer, non-binary, living with a disability, Romanian, a first-generation immigrant, and a white settler on Indigenous land. These are complex experiences that I embody everywhere I go.

This series was also my attempt at reconnecting with a past that I wanted

to forget when I was younger. When I learned about my HIV at 14, I turned away from Romania as a birthplace. This is a big regret of mine now, because I lost language and the ability to speak and connect to my extended family. I use Romanian titles as an attempt to regasp this "lost" language.

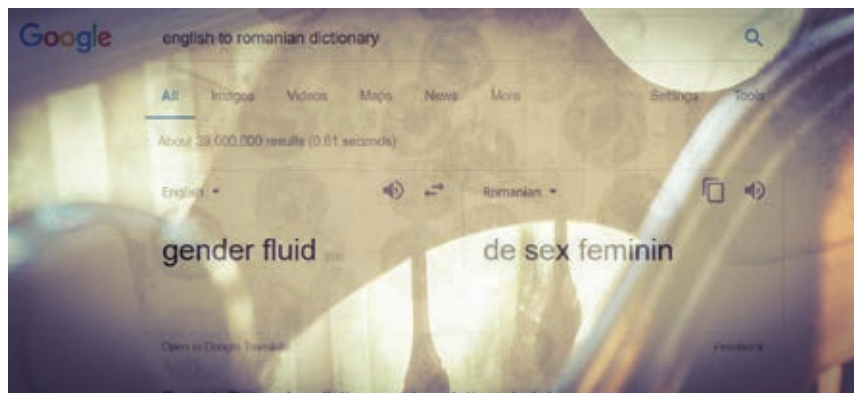
**J: In one of your writings you state, "I try to channel my inner sickly child in my work as an artist and activist today, listening back across time and the ocean for its hopes, fears, secret thoughts and longings. I wish someone had told me that my body is perfect just the way it is." Can you speak more to that?**

**D:** Coming to terms with my diagnosis was incredibly confusing and scary for me. Because I was so ill, I

I am the only poz person in my family. My family's relationship to HIV is complicated, and they tried some interventions in my teens and early 20s that I wish hadn't happened, but I understand. My mom is Orthodox and wanted to support me through religion, which never felt healing for me. I wish I had more community-oriented support when I was first diagnosed. It was hard navigating these things on my own. These days I talk freely about HIV with the women in my family—and they listen and support me in the best ways that they can, which contributes to my overall healing practice. I'm grateful for them.

Coming into my feminist self has really helped me grow and strengthen my relationship to my body and to my

*Întreruperea corporală [Bodily Interruption], 2019*



"The choice of overlapping images is a way of representing my complex experience of living with HIV."

was diagnosed with AIDS. It's like a time anchor: there is my life before diagnosis, and then life after. My illness created a lot of shame and anger, which I reflected inwards because there wasn't anyone to talk to about it—I didn't know where it came from. Eventually, I found out about the babies and children who were infected with HIV in medical settings in Romania. I was one of them.

HIV. I now feel a sense of agency over my body, my sexuality, and my gender identity. I needed someone to tell me, as a teenager, that living with HIV can be a normal experience and to not be scared.

**J: Queerness is an ongoing theme in your work. *Backgrounds* (2019) is one of your recent written works that speaks to your desire to reconnect**





*Să te faci bine! [Get well soon!], 2019*

**with your Romanian memories but also connect with community. In this piece you write that “HIV+ femme and queer bodies still get left out of history.” Can you talk more about this?**

I love my queer community—it’s where I feel the most authentic.

However, I’ve had a hard time finding an HIV community in the city, and I haven’t found where I belong yet. Once, at a prominent HIV organization, I was speaking to the women’s group and someone said that my non-binary identity doesn’t exist. I also heard a lot of transphobic comments in this organization. I didn’t feel comfortable going back, and there is nothing for queer and non-binary women/femme-identifying people. HIV discourse and service provision rely heavily on the binaries.

My art and writing try to bridge this gap. I make art for myself first; it’s deeply healing and therapeutic to

reflect on what’s going on inside and to make that visible. Anyone can be an artist! I truly believe that artists keep the world going. We all rely on or consume art in one way or another.

Conventional narratives of history leave lots of folks out. It’s important that we reclaim these histories and rewrite them for ourselves. Also, you [Jessica] were the first queer HIV-positive woman I’d ever heard about, in a women’s studies class at York University. We need more representation and mentorship opportunities for young, HIV-positive, queer femmes, and non-binary folks. I’ve felt alone most of the time, but I’m slowly finding ground and learning how my experience is connected to other HIV-positive people.

**J: It amazes me that almost 40 years into the epidemic, we’re still almost invisible. Where do you see your work going next?**

**D:** I can’t even believe it’s been that long and we’re still here! I’d like to continue exploring writing—it’s a very different process than digital art. I’m also an entrepreneur and curator. I run an online store for vintage clothing, antiques, and oddities, which allows me to explore my creative side while also paying rent.

Art is self-care and community care. By telling these stories, I am part of something bigger than myself and these connections matter. Art also helps facilitate connections and bridge differences between communities. I would love to collaborate with other folks living with chronic illness in making art. I’d love one of my future projects to be a collaborative zine or anthology created by queer and disabled folks. +

Jessica Whitbread is Canadian-born artist and advocate working in global movement building.



## CONTRIBUTE

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

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