

## To disclose or not to disclose? That is the question we posed to these 5 PHAs...



**Minneh Kamau, 35**  
Volunteer, AIDS Vancouver Island. Public relations, Cannabis Buyers Clubs of Canada. Diagnosed with HIV: 1993. Viral load: undetectable. CD4 count: 390. Victoria, BC

When I learned of my HIV status, I couldn't believe it. In the next seven years, I had four more tests...and I still couldn't believe it! *I was in denial, so afraid of HIV that I couldn't admit to living with it.*

My friends and family didn't know I had HIV until 1998. I didn't tell them because of the stigma and discrimination. Also, there was basically no treatment available for PHAs in Kenya, so I was afraid to say, "Hey, Ma! I've got HIV and I'm going to die soon." I thought I was going to die soon because I had no access to the medication.

When I came to Canada I heard about the new medications. I knew if I wanted to live, I'd have to stay here. It would have been foolish for me to go home to Kenya. *It was difficult for me to disclose my HIV status because of my immigration status.* I'm still waiting to hear the results of my application to stay in here, as HIV makes me inadmissible on health grounds.

To me, going home would mean death. HIV prevalence has reached epidemic proportions in Kenya, where around 1.2 million children are orphans, their parents having died from the virus. So many people have died that some Kenyans say they've gotten used to death. But people there don't talk much about AIDS.

In 1997, my daughter passed away in Kenya. She was 7. She was never tested for HIV but I suspected she had it because she always had many illnesses. After she died, I decided to go for a final HIV test, disclose my status and take it from there.

No matter where you live, discrimination remains an issue. I've seen people marginalized because of their status in Kenya, and I've known people subjected to discrimination because of their HIV in Canada. *Discrimination is especially hard on someone who hasn't come to terms with her HIV status.* Once I was finally able to accept that I had HIV, it was much easier for me to deal with all the issues around the virus.



**Duane Morrisseau, 34**  
National health coordinator, Metis National Council. Diagnosed with HIV: 1990. Viral load: undetectable. CD4 count: 500. Ottawa, Ontario

I had to disclose to two families because I'm adopted. As soon as I was diagnosed, I told my non-Aboriginal adopted family. They responded with "you're a liar." That was pretty much the final straw of the strained and abusive relationship I had with them.

As a young, Two-Spirited man, I needed support, but I had to carry the burden of having HIV by myself for a while. I lived in complete fear for three years. I started drinking heavily, feeling angry and sorry for myself, and inflicting harm on myself. I started drinking at 15 to numb things because of my upbringing. This was pretty much the scenario for coping with HIV, to force down my hurt and insecurities. But now I have a new approach: *Having HIV isn't about dying anymore, it's about living.*

After a few years of beating myself up, I moved to Montreal and got involved with AIDS Community Care of Montreal (ACCM). I was a mess, but ACCM supported me. I first spoke publicly about having HIV in front of 300 students and cried the whole time. The reception I got was so empowering, it melted me into a state of wanting to do more. I started publicly disclosing my HIV status in workshops.

*Disclosure started to open doors for me.* I was on the road to self-discovery. The more I disclosed, the more I discovered who I was. I discovered my Aboriginal ancestry. I moved back to Manitoba and started volunteering at the Manitoba Aboriginal AIDS Task Force. I joined the speaker's bureau and started educating First Nations people. The First Nations communities were in a state of high anxiety over this new dis-ease that was

foreseen by the elders. We were coming into their communities to teach AIDS 101, talking about addiction, alcoholism and family violence—things that affect our community—from a personal perspective.

When you disclose your status, there's a story that has to follow. *People want to know who, what, where, why, when and how.* So each time I disclose, I'm full of anxiety and insecurity. But when you talk about something for long enough, it begins to level out and become second-nature. You start to heal, but then you still need to deal with the foundation of who you are. Eventually, it becomes evident that the health issues you're talking about are a lot broader than HIV. I started to check out my background and searched out my Aboriginal family. I told my mother the first time I met her: "I'm Two-Spirited and I have HIV." I had nothing to lose. She said: "You are my son. I will love you unconditionally."

Though disclosing has been positive for me, *I don't go around disclosing to everybody.* I do it when I'm asked to do the work, and I do it with my heart. There are many levels of disclosure—your personal life, family life and professional life. I disclosed to my family in a much different way than I disclose to groups. The key is to find support within your community.

**Advice:** Hold your HIV status close to you. It's yours until you feel that someone in your life deserves to hear your story. Although there are laws that are supposed to protect PHAs, in my opinion, they don't. When I meet anyone now, I want to get to know them before disclosing, to avoid discrimination and stigma.



**Stephane Leclerc, 35**  
Volunteer, Méta-d'âme (an agency for people with addictions). Diagnosed with HIV: 1993. Viral load: 196,000. CD4 count: 200. Laval, Quebec

In the beginning it was real hard. Nobody in my neighbourhood knew about AIDS. I told my family; some of them cried, but it went pretty well. Then I started to tell some good friends, and they slowly started to leave. Out of 30 friends, I was left with only one.

*In bars when I'd disclose to girls, they'd think I was gay.* I'd have to explain every time that having HIV doesn't mean I'm gay. After disclosing, I felt like I was marked by the disease, that each time people looked at me they thought of the movie *Philadelphia*. I started isolating myself, crying a lot, and taking drugs and drinking to escape. When my father kicked me out of his home, I lived in the streets. I was tired. I had no support. I didn't know anybody else with HIV. This depression lasted for three years. I wanted to die.

Somehow I began to pull myself together—got a job and a place to live, started seeing my doctor and feeling better, stopped drinking, and started talking to my father again. Then I met my girlfriend, Chantale. A mutual friend introduced us, and it was *bada-bing, bada-boom!* When I met Chantale, I wasn't nervous or stressed, I didn't have to explain things. I felt good. Seven years later, we're still together.

*Being a straight man with AIDS is rough.* In the gay village, everybody knows about HIV, they know other people with HIV. With straight men, it's not the same. We're isolated. We don't talk about it. If you have it, it's your fault.

**Advice:** Don't tell people you have HIV because you want sympathy. If you don't have to tell or if you're not comfortable, don't say it. Take your time to be well with the situation. Take care of yourself, physically and mentally.

**Becky Beveridge, 26**  
Unemployed. Diagnosed with HIV: 1998. Viral load: unknown. CD4 count: unknown. Edmonton, Alberta

Telling my family was hardest. *I dropped a bombshell on my brother,* calling when I was drunk. He was the most understanding in my family. He told the rest of them and they treated me like a leper.

About a year after my diagnosis, I grabbed a bunch of pamphlets about HIV and the meds from HIV Edmonton. I mailed them to my family to help them understand about HIV and let them know I was going to be OK and that they could call somewhere to get more information. My stepmom read it, my dad didn't bother to look at it, my stepsisters refused to acknowledge the fact I had HIV. There's a lot of resentment there.

After I had my baby (he's going to be 2 soon...and he doesn't have HIV!), I was going through a hard time. I reached out to my family for help, but nobody was listening. I needed emotional support from friends and family and the only help I got was from agencies. I was really depressed. It felt like a never-ending battle. I ended up losing my son to child welfare. Until I find a job and a place to live, I'm not talking to my family. They don't know how to handle the truth or how to forgive themselves and me—for being homeless, having HIV, losing my son.

*Disclosing to friends has been hard.* Some have accused me of using HIV as an excuse. I'm always trying to defend myself and what I'm going through. None of my friends, except for those with HIV, really understand.

Dating disclosure is difficult. *I tell guys right off the bat that I'm positive.* I've had a lot of bad reactions. I almost got beat up in a nightclub once. I've never been sober and gone out of my way to try to meet someone. I've always done that under the influence, so I've never disclosed to a guy sober.

**Advice:** Use your discretion. When I found out I had HIV, I went to the

streets, told my friends who were drug dealers, got free drugs and fell apart for a year and a half. I wasn't a drug addict until then. I was disclosing to the wrong people in the wrong ways.



**Trudy Parson, 33**  
Peer support program coordinator, Independent Living Resource Centre. Diagnosed with HIV: 1991. Viral load: 58,000. CD4 count: 210. St. John's, Newfoundland

The opportunity to disclose was taken away from me when I was fired from my job as a home care worker. Before my diagnosis, I volunteered at an AIDS agency, so I knew that being fired because of my HIV infringed on my rights. I knew if I didn't protect my rights I'd allow people to treat me badly and devalue my life because I was HIV+. I had to tell my family right away because I was going to be involved in a human rights case with media exposure.

My mother's very protective and I couldn't imagine how I was going to tell her. I took a friend and a support worker from the AIDS committee along with me because *I was afraid of my mother's pain and didn't want to deal with it* on my own. They provided support to both of us, and the support worker provided my mother with practical info about living with HIV. It helped to know that I had people around me who knew I was positive and that it was OK. My mother told the family because I couldn't.

Though I didn't have to disclose to many people because the case was so public that my life became an open book, people did ask me inappropriate and stupid questions. I've learned that *I don't have to be wide open all the time* and that I'm not responsible for how people feel about me. Do I really care what the guy at the end of the bar thinks about my HIV status?

**Advice:** Disclosure is as unique, interesting and varied as the person and who they're disclosing to. Ask others with similar experiences about how they disclosed for different options to explore. I know people who aren't getting treated because they won't go to the clinic for fear of being recognized and identified as HIV+. If we took the fear away, it would be so much easier. At some point it's time to get on with your life: get a job, go back to school, get laid, have those babies you want. Keeping a secret, I don't know where you go with that.