

Teacher, Helper: My Relationship With HIV

Richard Jenkins

Tansi! My name is Richard Jenkins. I am a Cree/Metis from Moose Mountain, Alberta. I am currently living in Edmonton, where I have worked off and on over the years for the Nechi Training Research and Health Promotion Institute. I have been HIV positive for nearly ten years, and this article is about my journey with the virus.

I want to share my journey because it has been, by and large, a positive experience (no pun intended!). Of course, I do not like having HIV, and there have been many difficult and painful experiences along the way. But, the disease has also taught me many things, and the level of support I have received from family, from friends, and from work has been just amazing. I believe this disease has come to me as a helper and a teacher, a shape shifter that has given me access to many new insights and experiences.

My relationship with the disease started in the late 1980s. At that time, I had a partner who was HIV positive although I was not aware of his health status at first. For the three and a half years that we were together, we did not practice safe sex. I was a consenting adult in these relations, and, for my part, I just did not think I was going to get the virus. I figured, *"I'm young; it won't get me"*. I went for HIV testing several times during those years, and every time I was tested, I tested negative. These results allowed me to perpetuate the idea that I was not going to get the virus. I stopped testing for HIV in 1987, and when the relationship ended in 1989, my approach was, *"Well, I guess if I don't have it by now, I probably won't get it. I will just practice safe sex, and I won't get it."*

In 1991, I had moved to Ontario and was working for the Ontario Federation of Indian Friendship Centres (OFIFC). That fall, I decided it was probably time to go for another HIV test, just to check things out. I went for a test and after waiting the two-week period, I discovered that the lab had lost my results. It took me another few months after that to work up the courage to go and get re-tested. By the time I went back, they had found my original test results. I was informed that I had tested positive but that they needed to do another test to be sure because of the original lab mix-up. I was not really worried about it. I figured, *There has always been a possibility that I might contract HIV*; I am, after all, in a high risk group. It was like when I was young, and I used to walk across the field in the middle of the night, in the dead dark. I was terrified about coyotes, bears or wolves getting me, but I used to think, *"Well, if they are going to get me, they are*

going to get me. If it is my time to go, it is my time to go, and there is not a whole lot I can do about it anyway." That was my philosophy of life, and that was how I reconciled it to myself while I was waiting for my second test results.

When they called me in again and told me that, yes, I had tested positive, I realized that I was not as prepared as I thought I had been. I reeled for months: got depressed, got short and angry with people, went through the usual "Why me?" phase. I had a lot of guilt about having contracted the virus because I did not drink and I did not do drugs; I was not an intravenous drug user, so I really beat up on myself with thoughts of *I should have known better*. I did not blame anybody, but I did go through a period of self-blame. I knew that it was my own lack of prevention, and so, in a positive way, I took responsibility for it. But, I still felt guilty and ashamed, thinking, *Oh my God, I am a Queer. It is God's wrath on me*, knowing full well that it was not true. I also felt guilt and remorse about my sexual promiscuity. After several months of this guilt, I finally came to the realization, *"Well, you know, I could have cancer; I could have leukemia; I could have diabetes; I could have any kind of chronic illness. It is irrelevant how I got it."* I began to lose the shame and the guilt and think about how to work with the disease.

At first, I only told a few people about it: my boss and a close friend who was also HIV positive. I also felt it was important to tell people with whom I chose to have sexual relations, and I respected their choice not to have sexual relations with me. I did not talk to my family right away even though they had begun to ask me about it. The fact that they were even asking me was, I suppose, good. I had come out of the closet about being gay at the age of nineteen, so they were aware that it was a possibility that I might get this disease. But, it took me some time to approach them and to find a way of talking to them about my condition. I was living in Ontario, and the majority of my family was living in Alberta, so our contact was mostly by phone. Telling your loved ones that you have HIV is not something you do over the phone, at least not for me¹. I wanted to be with my family when they found out, so I arranged a trip home. I had a friend call and organize a meeting with my mother and my four sisters that were living in Alberta; I instructed her to simply tell them that someone was travelling to meet them and share some news with them.

The reaction from my family members was diverse. Some broke down and cried, processing bits of their grief immediately. Others did not display much emotion, downplayed the news, or seemed annoyed that this

¹ I had to tell one sister over the phone because I was unable to visit her.

news was something that they would then have to explain to their children. But, *no one blamed me*, which is what I had feared. After their initial reactions, they all simply asked a lot of questions, such as, How long have you known? and Are you sick yet? They had been paying attention to the reports and watching the news, a lot of which had to do with the horror stories about AIDS-related deaths. So, I told them, “well, you know, I could live forever. Or, I might walk out of here and get hit by a truck! I don’t know.” There is just so much that the medical profession does not know. So let us not bury me yet! So we managed to have some laughs about that.

The word eventually got around to my extended family, and to my relief, nobody disowned me. To them, I was still their grandson, their nephew, their cousin. Their approach was, “So you are HIV positive. Big deal. You are still part of this family, this community.”

In short, my coming out about being HIV positive with my family was almost anti-climactic. Their reaction was simply, “When are you going to come home?” Their response speaks to the love and acceptance that I have as a brother to my sisters, and a son to my mother. My family has never approached me as “my brother the queer,” or as “the one with HIV.” To them, I am simply a good brother, a good person, someone who does good work for the people. So it is that my family’s support acts as the foundation, the feather pillow on which I can rely when things become difficult.

My relationship with the community has grown from there. I am fortunate to have been employed by progressive organizations which have valued and honoured my role as a worker and as a community member. This was particularly helpful during a period where I had to live through the AIDS-related death of my former partner, Brockton. I had met Brockton in 1992 and had a wonderful relationship with him until he died in August of 1995. In the six-month period preceding his death, I was under tremendous stress which made it difficult for me to work. I was losing concentration, getting short with people, becoming easily angered and frustrated. I got to the point of handing in my resignation. My employer responded in a way that honoured me both as a human being who was struggling, as well as as a valuable employee. The executive committee of the organization for which I was working unanimously supported providing me with a paid leave of absence to enable me to assist Brockton through his dying process and to deal with my own related grief.

I returned to work a few months after Brockton died but was unable to manage the stress along with my grief. After six months, I went on short-term disability, only returning to the organization to finish some business before resigning. Again, my employer honoured me by recognizing me at their Annual General Meeting by presenting me with a gift, and by thanking me for all the good work I had done. I could have

continued working. My employer has always made me feel that my HIV status in no way impedes what I have to give as an employee. But, in spite of that supportive environment, I felt a need to go home to Alberta at that time. Toronto was not a good place for me emotionally, mentally, physically or spiritually. There were too many memories. I felt alone and felt a need to reunite with my family. I needed to be in a place where the pace was slower, where I could find that sense of community that I needed in order to regenerate.

The land called me home as much as my family did. While I was still in Toronto, the land would speak to me in my dreams. It was a draw. Sometimes, it was so strong I could feel as if I was home, sitting in the bush, or sitting at my house in Alberta, being around the land. Although I could call on the spirits to help me in the city, I wanted to be where my ancestors are most firmly rooted. I can more easily connect to "all my relations" in the land of Northwestern Alberta, in the trees, animals, rocks and plants of my home territory. And, being around home, being able to walk down the road, to see old places where I used to play and to feel the energy of the land was tremendously healing. Even simple things like having wild meat were positive and rejuvenating in terms of my health. I soaked in that environment, just as I soaked in the love and acceptance of my family.

It is three years later now, and I am healthy and working again in Alberta. My intention is to build my skill capacity so that I can return home at a later date, and for now, I am enjoying all of the lessons that continue to come my way. I am able to reflect on all of the teachings of my journey thus far, and I appreciate everything I have been given.

I now understand this disease to be a shape shifter. It is like those people in our communities who were traditionally known to change their form. They could shift themselves into a different physical space, taking on the appearance of a wolf, or a coyote for example. This new way of being helped them to survive, to go to different places, to access different things. Similarly, HIV shifts the shape of our cells inside, which thereby enables us to explore new ways of being, to see things differently, to play a different role. On a basic physical level, we are much more vulnerable to things which are going on around us because of the changes to our immune system. There are dangers involved, and HIV teaches us to pay more attention to our bodies and the environment in which we find ourselves. But, if we pay attention, we can see and be aware of all kinds of good things too. Our sensitivity can open us up to all sorts of new possibilities on emotional, mental and spiritual levels.

I am learning to work with this helper, this spirit which has come to teach me something about life, about faith and belief and about what community means. The strength I have taken from this teacher has

manifested itself on several levels in my life: from individual, to family, to community.

Self-Acceptance.

It was a struggle to accept that I had HIV, as it is a struggle for anyone with a chronic illness to accept their disease. People who find themselves in these circumstances need to work at accepting that they are not somehow weaker or less human than before they had the disease. This struggle ties into overall issues of self-acceptance. Unfortunately, some people react in a negative way, and they become harder not only on themselves but also on other people whom they perceive as being weak as well. I have simply come to accept the disease as a new way of being in the world, and this acceptance has been a liberating experience.

For those of us who are HIV positive as well as homosexual, acceptance of the disease is linked to our self-acceptance around sexual orientation. If we have contracted the virus through sexual activity, it can evoke old feelings of anxiety or shame about what other people will think of us, and maybe about how we think of ourselves. These feelings can be even worse if a person's family or community are unaware that he or she is gay. I was lucky because I did not have to worry about my family. I have seen some people suffer shame and guilt they think, *Oh my god, I am HIV positive, and I will probably get AIDS, and then I will die and my family will find out that I was gay, and they never knew.* Even so, my first few months with the disease were not without the anxiety and blame which often accompany the first stages of a relationship with HIV. It was like a relapse to a time when I would worry about how other people would see me because of my sexual orientation. For a brief period, I saw myself again through the negative lens of other people's eyes.

Telling my family was helpful in terms of self-acceptance because their support gave me the strength to see myself just for who I am. This self-acceptance was critical in terms of dealing with negative and anxious feelings when they tried to creep in again, such as the first time I spoke publicly about my journey with HIV. I had decided to give a talk at a health conference, and, in spite of my confidence that I was doing the right thing, it did cross my mind that people might no longer perceive me simply as Richard Jenkins; that I would become "that faggot with HIV." In the end, it was liberating to speak publicly about my HIV status because it confirmed my understanding that *I* am the one who creates my image. If other people wish to see me in a negative way, those images belong to them.

To me, the most empowering tool we can have as individuals is self-acceptance. If we can see ourselves in a positive way, what others see becomes less important. As a gay Aboriginal man who is HIV positive, I

have had plenty of opportunities to put this into practice. My experiences have taught me that I do not have to wear other people's negative images, be they about Natives, homosexuals, or people with HIV, because those images come out of *their* negativity. And, I find that the more I have this positive attitude about myself, the less I see negative attitudes in other people. I do not engage in negativity and shame about HIV, so I do not invite it. I surround myself with positive, accepting people, and that is my reality. When negative people come in contact with me, I see something different, and they, in turn, respond. Thus, the more I create my own image, the broader it becomes in my mind. The bigger it gets as a picture, the more it comes out of me. I find, too, that people want to be around that type of positive energy; they want to discontinue their own negative thinking.

It is important to accept that having HIV does not mean that we are any less worthy of love and acceptance from ourselves, from the Creator, or anybody else. I know that I am worthy of love. I am worthy of my own love, and I know that the Creator is totally accepting and full of unconditional love for me.

Building Support

Once I had developed self-acceptance, it became easier to build support networks around me. I believe that the acceptance moved from me, to my family to my community.

I am lucky because my family has always been supportive. They are my foundation. For this reason, even though I am in Edmonton now, I maintain regular contact with them. I phone a family member almost nightly because this is my way of maintaining those relationships that are so important.

My family accepts me and loves me for who I am. This acceptance is sadly not the case for every person who is HIV positive, but there are ways of developing that inner circle, that "family" in the absence of a supportive biological family. (And, if we can not find that type of "family" acceptance, it is perhaps worthwhile to revisit our own self-acceptance). With that inner circle of support, we are more able to go out and proactively engage in the community. For example, it was my family's support and acceptance that gave me the strength to be public about my HIV status. Most people whom I know and with whom I work are aware that I am HIV positive, and this knowledge is not a hindrance to my participation in community life. I have been fortunate over the years to have been employed by progressive organizations who value my role as a worker and as a community member. They have enlisted progressive policies to support me in my times of need, and they have honoured me. Because I have that support, I do not have to worry about someone not hiring me because I have

HIV. I know that I have a community that supports me and recognizes me above and beyond the disease.

Relating to purpose: Seeing value in my role as a community member

Being HIV positive has allowed me to reflect more about community, about the support I receive from community and about my role within community. My family's response to the disease has been to appreciate the many skills and teachings I have to offer them and to my community back home. The fact that there is a perception that I could die in the near future has reminded them to call on me to come and to share what I have learned.

The role I play as an uncle is a reminder about the value of extended family and community – that it takes more than just two heterosexual parents to raise children and to make the community work. Some of my sisters say, "I want my children to benefit from what you have to offer." As an uncle, I know I have parental responsibilities in the true sense that it takes a whole community to raise a child." Because I want my nieces and nephews to benefit from some of the opportunities that I have had, my focus has always been to bring home what I have learned from the many years I have spent working and learning in Ontario.

I believe my purpose has always been to be a servant of the people. I am now even more secure in the knowledge that I am a vibrant part of the community. I know I have something to give and that I am honoured and respected for what I have to give.

Having Faith

I have always had the simple faith that death is merely a passage to a different place, a different reality, a different place of being. Being HIV positive has brought me that much closer to a realization of death. It has led me to contemplate my own mortality--something that most people do not go through until later in life. In turn, I have been the primary caregiver for a partner who died of AIDS and that experience has taught me many beautiful things.

The biggest lesson I took from my former partner Brockton's passing is that death does not have to be an exclusively somber and sad experience. I see it as a journey back to the spirit world, back to the Creator, and so, in that sense, it is incredibly joyous. As the primary care giver for Brockton, I had the privilege of traveling with him on that journey as far as I was able. There is a real joy to be experienced in being that close to the doorway; watching Brockton communicate with the spirits as he got closer to death was a powerful awakening. In this awful physical time, spiritually,

he was going through a real chrysalis process. It was as if he was coming out of a cocoon--he was a butterfly spiritually, and I was witness to that process. So, to some extent, as a primary caregiver, you also go through a transition process, a dying process. I was able to open up to my faith that the spirit helpers were there; I was reminded of those things that I already knew.

I carry the joy from that experience today. I have seen others so heavy and joyless in their partner's passing and wish that more people could be open to the joy of being that close to the doorway--that joy one feels in witnessing a spirit that has gone home. I remember at one point talking to an Elder who has helped a number of people pass away. She said to me, "I don't know if I can help any more people. The next person I might want to go with!" And, now that I have had that experience, I am not as afraid or as saddened by death. I see it as an honour to integrate all of those teachings into the rest of my physical life.

Lightening up!

Finally, when things get so serious and somber, it is a good reminder to us all to lighten up! I believe that if I think in a certain way and act in a certain way, I will prolong my life. My health will become better if I have a positive attitude and especially if I have a few laughs along the way. I may not like having HIV, but I have accepted this disease as part of my life now and have integrated it into my journey.

Maybe some day I will make amends with this spirit, this helper-teacher called HIV. Maybe some day I will make the deliberate choice and say, "Okay, I have learned what I need to know from you. I can release you now," and maybe then it will move on. In the meantime, I will remain open to the lessons that it has to offer about life, about community, about love. I do not see myself as a victim. I do not see myself as a survivor. I see myself as a celebrant of life.

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