

HIV/AIDS and Aboriginal

BY CATHERINE BAYLIS WITH BRENDA LOYIE

Brenda is worlds away from her old life; she is also just one slip away from that old life. She has traveled further in 37 years than most of us could ever imagine traveling in our lifetime.

C'est en relatant les expériences d'une femme autochtone diagnostiquée VIH/sida que les auteures nous renseignent sur les problèmes des autochtones, des travailleuses du sexe, des utilisatrices de drogues à injecter et d'autres groupes marginalisés qui vivent avec le virus. Cet article nous sensibilise aux besoins des femmes qui doivent être informées pour se garder en bonne santé, depuis la prévention jusqu'à la gestion du VIH/sida

Brenda is one of three Aboriginal women who are the subjects of an autobiographical video outlining their challenges and accomplishments with HIV and substance use.

This documentary video was developed by an AIDS service organization, AIDS Prince George (AIDS PG) in partnership with Pattison Broadcasting. "Women, HIV and Addictions: Before, During and After" is intended to be an educational tool for those who work in the field of HIV/AIDS, substance use, and other areas of marginalization. This video is the focus of a workshop, developed by AIDS PG and co-facilitated by Brenda, to address the use of video as an educational and therapeutic tool. In addition, a booklet is being developed to enhance the usage of the video.

Brenda is also the focus of another educational video project for healthcare professionals and other service providers who are involved with Aboriginal women. In "Hospital Curtains Are Not Walls" Brenda will address her concerns and experiences within the health care system around HIV/AIDS healthcare for Aboriginal women, sex trade workers, injection drug users, and other marginalized groups. Brenda will also discuss the need for enhanced sensitivity regarding issues of confidentiality and ways in which hospitals, and other health service organizations can better ensure privacy and confidentiality. She will also talk about the need for women to be informed and involved in their own health care from prevention to management of HIV/AIDS.

Brenda is worlds away from her old life; she is also just one slip away from that old life. She has traveled further in 37 years than most of us could ever imagine traveling in

our lifetime. When she speaks to me of her journey, I am humbled by the strength and determination with which she forges ahead despite the never-ending roadblocks she encounters. I am also humbled by the grace with which she conducts herself in a society that often judges her according to her past. She embodies the spirit and strength of every Aboriginal woman I know and I am honoured to write her story.

Brenda is a Cree woman from Northern Alberta. She is very much her own person. She is also a mother, a partner, a daughter, a sister, a niece, a cousin, an auntie, and a *kookum* (grandmother in Cree). She is a friend, a co-worker, a feminist, and always an inspiration. She is the Peer Counselor and advocate at AIDS Prince George. She has multiple diagnoses of HIV, Hepatitis C, and Hepatitis B. She is battling diabetes, chronic bronchitis, and other physical ailments that are a result of her multiple diagnoses. She struggles with addiction to injection drugs.

Other than a brief period of time when her parents separated and her home life disrupted because she had to live with her grandmother, Brenda had what she claims was a happy childhood. By the time she was 21 she was married with two small children. Her husband worked while she raised their children. Her life was "normal."

But, when Brenda was 21, her sister Sharon was murdered. It was a horrific death. She and her sister Sharon were very close. When they were kids their mother used to dress them in identical clothing and people thought they were twins. Like most sisters, even though they loved each other dearly, they sometimes fought. The last contact Brenda had with Sharon was during one of their arguments. Sharon was shot in the head with a rifle. The person who shot her has never been held accountable and so, in the courts, her death is recorded as a suicide. Her family knows differently. The pain, the loss, and the lack of justice haunt family and friends still. The ensuing 15 years has not lessened the impact of Sharon's death or the implications of a system that failed to address the murder of yet another Aboriginal woman in this country.

Brenda was devastated by her sister's death. She went on a drinking spree that lasted more than ten months. She left her husband. She knew she was not in any shape to take care of her kids so she put them in her husband's care. She got a job in a bar in a small northern Alberta community. She lived in a room she rented above the bar. She ate, drank, worked, and slept at the bar. The alcohol dulled her

Women

One Woman's Story

pain and deadened her feelings. That was all she wanted.

It was in that small northern community that she first injected drugs. Brenda had a fear of needles. She couldn't stand the thought of poking a needle into anyone, least of all herself. Someone else did it for her. She lay on a bed with her arm outstretched and a pillow over her face while the other person made the injection. That first needle contained Talwin. The relief from the emotional pain was instantaneous. She realized she could achieve emotional numbness without having to drink all that alcohol. Things progressed quickly from there. The need to numb the pain was replaced by a need more consuming than anything she had ever experienced. She became addicted. For at least a month after her first high she needed someone else to shoot her up. It didn't take long, however, before her fear of needles disappeared and she was able to inject herself wherever necessary—even in her jugular vein.

While Brenda was using drugs, her first two children returned to her care and she gave birth to three more children. One of those children was born addicted to heroin. The Ministry subsequently attempted to apprehend all of her children. Although she had just given birth and had very little energy, her survival and protective instincts kicked into gear. She arranged for others in her family to take the children into their own custody. As a result, none of Brenda's children ended up in foster care. Despite those years of injection drug use, Brenda always made sure her children were in the care of family members whenever she was unable to care for them herself.

At times, Brenda supported her drug habit by working the streets. Brenda was often a "collector" for drug dealers and collected debts from other working girls. She was well known as a tough person that others did not want to cross, but there was another side to Brenda. Even while using injection drugs, Brenda would counsel others to get their lives in order and try to stop using drugs.

At some point, Brenda contracted HIV, Hepatitis C, and Hepatitis B. She was diagnosed with full-blown AIDS in 1997. At the time she was gravely ill, she weighed 97 pounds and was literally at death's door. This was a turning point in her life. She knew she would not survive unless she made drastic lifestyle changes. Brenda began her first HIV treatment regime and went on a Methadone program. She had connected with the local needle-exchange program and was one of the first to register with that agency. The support of the nurse who operated the

needle-exchange then—and still does—played a key role in Brenda's recovery. Today, they work closely as peers to provide services within the community.

The HIV medications helped reduce Brenda's viral load and increase her CD4 count. Although her viral load went from 750,000 to an undetectable level, the HIV medications were hard on her body. She suffered severe pancreatitis and was forced to try a different medication cocktail which she was better able to tolerate. However, about three years later the HIV mutated and became resistant to the medication she was taking. When that happened, she

went off all HIV medications. Although Brenda has gone from having full-blown AIDS back to living with HIV, her state of health has been a roller coaster of opportunistic infections.

Brenda has had both good and bad experiences while accessing services related to HIV/AIDS. Once, she walked out of the hospital while being prepared for hernia surgery. She was frustrated with the medical staff's refusal to listen as she tried to tell them which veins they would, and would not, be able to use for the intravenous. After many painful and futile attempts to draw blood from veins that have too much scar tissue to allow access, and feeling judged based on the colour of her skin, the tattoos on her arms, her HIV status, and her past as a sex trade worker and injection drug user, she wrapped the sheet which covered her body around herself and stormed out. Two weeks later, her hernia ruptured and she needed to be admitted for emergency surgery.

Brenda says that if the medical staff had listened to her and valued her opinion she would never have ruptured her hernia. She feels strongly that many people do not hear the "ex" part of "ex-sex trade worker" and "ex-injection drug user." Healthcare professionals have talked clearly about her HIV status in front of her children, to whom she had not yet disclosed, and loudly enough to be heard through the curtains that separate one emergency cubicle from another. Brenda is committed to addressing issues such as these in her work as an HIV

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activist, advocate, and Peer Counselor.

Brenda has also had positive experiences with the health care system that deserve mention. There are lab technicians who show their respect by inviting her to direct them to the veins she thinks will allow them access. She has a doctor who ensures that she is actively involved in her own healthcare and treatment. There are healthcare professionals and service providers who acknowledge her skills and value her experiences by seeking her input, advice, and assistance in their efforts to provide healthcare and other services to her, as well as others, who are living with HIV.

Brenda gets a lot of support from the local AIDS service organization, AIDS Prince George (AIDS PG). She initially accessed services at AIDS Prince George at the urging of another Aboriginal woman living with HIV who was connected to the agency. When Brenda first came to AIDS PG she was angry. That anger was, in part, a result of her diagnosis of having HIV/AIDS. Another part of her anger was the result of her struggle to stay clean and to cope with an unknown future in terms of her health. She also finally had to face the pain of her sister's death many years earlier. Her anger was a coping mechanism and a protective shield, a wall she had built to keep her safe in the volatile drug world she had been living in for over a decade. It took her some time before she began to trust that she would be accepted and treated with dignity and respect. Gradually she began to open up and accept the support she was being offered. As she began to get other areas of her life in order, some of her children were returned to her care. She became actively involved in the management of her own health and honed her natural advocacy skills.

Brenda began to volunteer her time to AIDS PG and eventually took part in the peer counselor training. She became the Peer Counselor at AIDS PG and used her advocacy skills to assist others living with HIV as they dealt with their issues around HIV/AIDS, poverty, racism, substance use, and other social determinants of health. As Brenda's confidence grew, so did her skills and abilities. She began to define the role of Peer Counselor at AIDS PG as she became involved in HIV/AIDS work at many levels. Today she provides support and services to people who are living with HIV/AIDS. She models self-advocacy and acts as an advocate. She is also involved in the community education that AIDS PG provides. She is the needle-exchange's positive delegate for the Pacific AIDS Network. She is a member of the Northern Interior Health Region's Partners in HIV committee and she has been involved with the Canadian Aboriginal AIDS Network. Her involvement in HIV/AIDS work extends from the agency and community level to the national level where she is also a member of the Canadian HIV Trials Network.

As Brenda continues to live with HIV, she wishes her mother was alive to witness her many successes in recent years. She takes great pride in her children's accomplishments as they achieve high grades in school. She knows her stable home life contributes to their successes as well.

She recently began another round of treatment with a new cocktail. She had a severe, potentially fatal reaction to Abacavir and once again had to abandon her treatment regime. She is currently without medications, hoping that a new, effective cocktail will be developed that she will be able to tolerate.

For the most part, Brenda says that contracting HIV has been a blessing in disguise. It forced her to change her life. Those changes have been incredibly beneficial for Brenda, her children, and those who are close to her. Her new and healthier lifestyle is a great benefit for AIDS PG staff and clients. She is an inspiration to others struggling with many of the same issues. While Brenda has come to terms with most of her past, her future is unknown. She thus lives very much in the present, grateful that she has the opportunity to participate fully in the productive life she continually creates for herself.

Catherine Baylis is of mixed Ojibway and Scottish ancestry. She is currently employed with AIDS Prince George as the Client Services Coordinator. She and Brenda work closely together in providing support and services to those infected and affected with HIV. Catherine has spent the past ten years working in Prince George, B.C. in various capacities with Aboriginal people. She recently completed her Master of Education degree at Simon Fraser University in Burnaby, B.C. She is combining her love of writing with her passion for issues of feminism, particularly those issues that impact Aboriginal women, by writing and compiling a collection of Aboriginal women's life experiences with oppression and marginalization. Catherine is considering continuing her education to complete a PhD.

Brenda Loyie is a Cree woman. She is the Peer Counselor/ Advocate with AIDS Prince George. She has lived in Prince George for 34 years. She has been clean for four years.

Shirley Adelman

Vanishing

My daughter has disappeared,
not in one full swoop like one
who runs away while on an errand,
but slowly, pound by pound, week by week,
until her face became all eyes and mouth,
like an ancient mask stored far from sunlight.

Shirley Adelman's work has been published in the United States, England, and South Africa, most recently in Lilliput Review and Jewish Affairs.