

Voices of Women Living with HIV

by Carol Devine

Des femmes de couleur séropositives partagent leurs expériences de vie avec le SIDA. Quoique leurs vies diffèrent grandement, elles ressentent toutes l'isolement parce qu'elles sont femmes

de couleur et séropositives/sidéennes. Elles sont non seulement victimes de discrimination dans certaines situations particulières mais elles le sont également à l'intérieur de leurs communautés.

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Women's experiences living with HIV/AIDS differ widely. Many do not have the same race, sexual orientation, religion, or a unifying community. Women of colour living with HIV/AIDS experience some commonalities: multiple isolation because of their gender, race, and serostatus, and discrimination in some settings, including in their own communities.

"I was already struggling with an addiction when I found out I had HIV. I got worse when I found out. I thought, well, if the addiction doesn't kill me, the HIV will. But then I started trying to eat properly and dealing with it and my count is going up." She is referring to her T4-cell count. It is a measure of a type of blood cell important to the body's immune system.

"I have been living with HIV for four years," says Karen. "Life is frustrating at times. I can't do what I used to." She says even going to the store is a chore—she gets very tired. "It is just hard living. I feel something is inside of me that shouldn't be there... There are days when I cry and get down. There are days when I just enjoy life."

Karen says her health is "so-so" at present. She has constant inflammation of the muscles—basic arthri-

tis—that doctors first thought was due to her brief treatment with AZT, the drug often used to treat infection in people with AIDS. She tried AZT at one point when her immune system was low, but "they took me off it because I had side effects—headaches. It is too toxic." Karen says she's slowly learning how to eat properly. "I hope to try herbs, but I am so busy, so many other things are going on in my life that I don't have much time to think about these other things."

Karen found out she was HIV positive from her mother. Her young son went to another country to live with his grandmother. Karen's family knew she had a drug addiction, so they tested her son for AIDS. He tested positive for the HIV virus. And then she went for testing too, "and of course, I was positive."

"My mom is very supportive. She has been a big part of my support system. But phone calls are very expensive!" Karen doesn't see her son often but she will this summer after two-and-a-half years. "It is so hard to know he is living with the disease too."

Karen also gets support from working on a project for an AIDS Service Organization. "The women I work with are a big part of my support system. We are there for each other, but we also give each other space," she says. Karen is also involved with an AIDS Service Organization for people of colour which provides her with some additional emotional and financial support.

"Two years ago I started to get in touch with groups for people living with HIV and AIDS. It was scary at first to go to support groups because most of the women in 'women with HIV' groups are 'normal,' or what society calls 'normal'—from the suburbs. As a former prostitute and person living with an addiction I was nervous to go to the first meeting. But then I was totally open and I was given support. Once I got there they helped me. But

I don't want to get too involved with [HIV/AIDS] agencies. Because I have it [HIV], I don't want to own it," she says. Karen thinks that all people need to "own" the disease, i.e. get involved in AIDS activism and support, not just people living with HIV/AIDS.

"I live a double life. Most people don't know [I am living with HIV]. People just don't want to hear about it. Friends who don't know I am HIV positive say 'those people should be put somewhere else.' It is hell living this way. I dare not tell—it's all hush-hush."

"As a woman of colour, I get a lot more support from the white community. In the black community, people think if you are living with an addiction, you are a slut. I have been rejected from my community also because I am HIV positive. I am isolated from the community because people still think it's a 'gay disease'. There are so many close-minded attitudes. Some men have been accepting, but that's because they think they can get into my pants." She says women consider her promiscuous. "Women don't accept me unless they have the same lifestyle."

Karen talks about the fear of and misunderstandings about HIV and AIDS that so many people have, "People even see information, books about HIV and AIDS and they say 'get it away from me.'" She says, "Doctors and nurses are scared of us, and if they are scared, who won't be?"

"I think we have to educate children. Then the children won't be afraid and they'll tell their children and the information will be passed on... People need to know that HIV is in every community, every group," says Karen. "It just doesn't happen to the lower class—I've met people from the suburbs who have it. I call them 'suburbia' (laughs). It's everybody's disease—it doesn't have a colour."

What she needs now "is a proper

place to live. I owe the government for my past life and they won't give me grace." She says "As women, as people with HIV and children there is nowhere to live. They keep forgetting that we have children and a family. People need to be understanding and non-judgemental. The fact is, we're here."

Fasika learned she was HIV positive in the summer of 1993, when she and her husband planned to get life insurance.

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Through a social worker, Fasika got involved with AIDS service organizations very soon after learning she was positive. Her social worker first introduced her to an Af-

rican woman who he said would be an excellent person for her to speak with. "This woman was a very good help." They speak the same African language so Fasika feels comfortable with her.

She says she really appreciates the acceptance she's had in the AIDS-related agencies. "All the people I have met take me the way I am."

It really helps, she says, to speak to other HIV positive people. "For people from our country it is not easy to admit you are HIV positive. It doesn't matter, you don't need to tell people if you are HIV positive or not."

Fasika met people right away who told her "Get in touch with this person and that person' and I'd go to them. I love to learn more, it is good for me and I can then help other people. If I met someone from my country [and found out they were HIV positive] I would talk to them and want to help them." But she says, "I don't blame people who hide from telling other people. I keep my problem secret from my community otherwise I might not be included."

"Everyone would live together better if people were understanding. When I go to gatherings, I wonder if they knew I have HIV [would] they would accept me? Sometimes I wonder if I am doing something wrong,

but I know from speaking with other people that I can do them no harm, so they don't have to know my problem. When I hug them and chat with them, it's natural to think 'would they be nice to me?' Then I think, they don't know either, some of them could have it."

The first people Fasika and her husband told were a couple, old friends, who were very accepting. "They have offered their spare time to volunteer on our behalf, and they try to learn about HIV and AIDS... I can cook food and they eat it with pleasure. We can eat together and feel happy."

When Fasika learned she was HIV positive, she was four months pregnant. She decided to have an abortion. The hospital wanted her to wait two weeks, until she was four-and-a-half months pregnant before she had the abortion. "The two weeks waiting for the abortion were very difficult," she says.

Fasika got counselling before the abortion both at home and while she was at the hospital. "Every morning the nurse talked to me. She was very nice." But Fasika also experienced discrimination at the hospital.

"The only time I felt my colour was at the hospital getting an abortion. My roommate was white and not positive. I felt she got more attention." Fasika was feared. The hospital was concerned about the blood she would be losing after the abortion and infection control—and couldn't handle the situation without treating Fasika very poorly. The hospital eventually sent her a letter of apology after she made a complaint.

"I can't do anything about the abortion. Thank God now it's all over. I'm not happy, I'm sick. But I'm happy I can live positively." Fasika's young daughter is not HIV positive. "She is a lovely, healthy child." Although her daughter was born while Fasika had HIV, she tested negative, as do the majority of children born to HIV-positive mothers. Only ten to 30 per cent of children born to HIV positive mothers are HIV positive. But Fasika says she is still scared to take

her daughter for blood tests again. "I know I shouldn't be worried, but it scares me. If my daughter were positive, that would be another life."

She told her good friends, the supportive couple, "Take our daughter away. I was so scared to give it [HIV] to her. I found out that I could not give it to her just from eating and living with her. The couple said, 'No, you're young, we're old' and that I should take care of her." Fasika says, "I hope to live to bring up my daughter so that she knows what is good and bad." She says she would want to do this anyway, because she could get run over in the street. "Having this is like having cancer."

Fasika's parents are also accepting. They live many miles away, overseas. "My father wrote to me that he just believes we are born one day and we will die one day. He is strong." Now AIDS is common where her parents live, but she says it is still not easy to know their daughter is infected. "I think it has affected my mother more. My father wants to protect my mother from news of my health. He told me to call later when my mother wasn't home if I had anything wrong with my health. I think I've lived with it positively because I have so much support. Because my parents are accepting I know my daughter will be in safe hands."

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He's weak, he doesn't want to talk. He gave it to me, he fooled around, and I'm the one telling him to live. It's not the other way around—I'm telling him to accept it. When I found out, I was not mad. I had it and I couldn't do anything about it. I believe God has written for me to have this disease. If it wasn't from my husband, it would have been from

another man. I truly believe it." Fasika says because her parents never blamed her husband, "I have more courage."

Work is very important to Fasika. Her daughter goes to school and she and her husband have a babysitter. "I need to go out. If I sit at home, I'll be bored and I'll start to think about it. Since I found out about my problem, I wanted to work with people who deal with it." Fasika works at an AIDS service organization. "God has accepted my prayers—as long as I have a job. Here I'm free, I can get assistance. I am happy to work with such people who accept me. Part of my life is here in the HIV community." It is also a new social network. With the new people she and her husband meet, "Maybe we can get together on the weekends."

Fasika is healthy at the moment. She is not taking any medication but tries nutritional supplements. "I have to stay healthy now," she says. "I try to eat bigger portions of food and I've put on weight. I don't care if I get really big!" she says. The amazing thing she says is that she always tried to put on weight before she found out she was living with HIV, but she couldn't.

"I do everything that is important for me. I eat as much as I can, I get plenty of sleep, but I don't like exercise though (laughs)! I live just normally."

Carol Devine is a writer on human and women's rights issues. She has recently published the book, Determination, Tibetan Women and the Struggle for an Independent Tibet by Vauve Press.

Specific Needs of Aboriginal Women

Women are perceived as caregivers in Aboriginal society, that is, they care for the children, feed the family, care for the infirm and elderly, and generally provide the traditional services of the homemaker. Although there are deviations in an urban setting, the pattern does not change appreciably in the smaller rural and reserve communities. Often, these women, whether they live in a rural or urban setting, are hard to reach because they are usually tied to the home and the needs of their families. Moreover, these women are often on the receiving end of sexual abuse, spousal assault and other social conditions that lead to diminished self-esteem and confidence.

"Women are the key for the community. Where the women are healthy, you have a healthy community."

With the number of AIDS cases among Aboriginal women increasing, it is safe to assume that the number of HIV positive Aboriginal women is also increasing. Anishnawbe Health, Toronto reported that during the period August 1991 and August 1992 they encountered a dramatic increase in infected Aboriginal women and Aboriginal women seeking HIV counselling.

"Our community is small and I think there is a lot of denial here, which is scary."

During the Second National Conference on "AIDS and Related Issues Among The Aboriginal Population" held in Vancouver in January 1991, two Aboriginal women—one Indian and one Inuk—related their HIV/AIDS histories. They spoke about conditions surrounding their HIV infection; in both cases, injection drug use, heterosexual contact with an infected sexual partner, and alcohol were risk factors.

Sexually Transmitted Disease (STD) levels among Aboriginal people continue to be high and in some areas three to four times the national average for some diseases. The incidence of pregnancy among adolescent Aboriginal women is also higher than the national average.

From a sexuality perspective, it has been pointed out that many Aboriginal women lack power and assertiveness in a sexual relationship, and this is especially true for young Aboriginal women. The fear of abandonment and violence precludes the insistence on safer sex practices between partners and discussions on sexual histories.

Aboriginal women are at high risk for HIV infection because gender role behaviours between Aboriginal men and women make it difficult for a woman to insist that her partner practice safer sex. Women who are concerned about birth control and sexually transmitted diseases may not be given the opportunity to practice safer sex because men often define when it is appropriate to use condoms. The result is that women suffer the consequences of high-risk behaviours.

Excerpted from the Aboriginal Nurses Association of Canada, March 1993, Report HIV/AIDS and the Impact on Aboriginal Women.