

Living with HIV: Frequently Asked Questions

Alex Archie

What was the first thing you did when you found out that you were HIV positive?

I was in a combination of shock and denial. If it weren't for the mixed emotions, I would have probably cried. I believe that I did cry eventually. I had been sitting in this nurse's office waiting for a while, thinking that it shouldn't be taking this long. Then, I realized that I already knew that I was HIV positive. The nurse who took my blood two weeks before came into the small office, said hello without looking at me and sat at the desk. He put my file on the desk, sat in the swivel chair and turned to face me. He smiled; I smiled. I could tell from the way he was acting that he wasn't going to tell me anything that I didn't already know. Finally, after listening to his well-rehearsed lines about sex, safer sex, my limited treatment options (in November of 1990), and whether or not I had any questions, I was in a daze. So, the first thing I did when I found out that I was HIV positive was walk out of the walk-in clinic.

The next task was to find my way home. After waiting tables during the lunch rush I wanted to get home and take a nice hot shower. I was thinking that the nurse could smell me as soon as he walked into the tiny room. Looking back on it now, I suspect that he probably thought it was best not to say how bad I smelled because he had some pretty bad news. My day was filled with enough devastation, but the dogs that lived on the streets leading back to my apartment didn't know that. They still smacked their jowls and barked, jumping up and down on the fence. Pizza! They wanted me because I smelled like pizza.

My best friend/roommate was home. I told him. He said he could tell by the look in my eyes. It must have been the desperate, scared, hurt, far away stare that I had on my face. The second thing that I did was take a hot shower, almost believing that I could wash this away, that maybe I'd wake up in the shower, and this would all be just a dream.

The feeling of denial was the first emotion that I felt the strongest. It was the only emotion that I was able to stand being alone with if that is possible. Maybe the most interesting aspect of this time was that I could be in total denial and still function.

Do your family and friends know?

Of course they do. They've known almost all along. They may not have been able to deal with it, but they were right there with me learning as fast as they could. My Mom is a part of the Circle of Life HIV/AIDS Support Group, a new group that had just been started on my reserve at the time of my diagnosis. They have a policy regarding people living with HIV on our reserve. It is positive and states that no one shall be discriminated against if they are HIV positive.

How did you get infected?

Drunk, stoned and stupid. I was stupid enough to believe that I couldn't get infected. I was stupid enough to believe I knew enough when I left high school about the world and that I would live long and prosper.

When did you start living with the Human Immunodeficiency Virus?

Living? I remember when I was first diagnosed, back in 1990, that the only thing I could think about was *dying*. I felt the only reason that I was living was to die, which, of course, is true for all people, that and paying taxes. I planned my memorial, who would be there, what songs they would play. We would have it at the gym on my reserve. I was raised Catholic. Hail Mary full of grace. It is not that I don't appreciate other people's beliefs, it's just that there is no allowance for Two-Spirit people in the Catholic Church. The Church believes I am immoral and don't belong in the Kingdom of Heaven. That is why I want my memorial to be in the gym. I hated myself most of my life for being a Two-Spirit person, for being different, and I even attempted suicide. I guess I don't want to mislead the Church; they may think that I changed, that I accept their doctrine of discrimination and hatred.

At this memorial, I want people to see how many people knew me, to see how many people liked me and how far they would travel to pay their last respects. I haven't checked with my brothers yet to see if it's okay that they won't be pallbearers. I want some of my friends to have the responsibility. My brothers will have to support my Mom and Dad as well as their families. I have asked a former Chief from the Mohawk territory in the region known as Quebec, my best friend from Dallas, Texas, another friend from high school who is now in Edmonton, and my crazy best friend from when I was a brat on the reserve. We used to do crazy things, like our secret little gang, *The Borrowers*. In regards to *The Borrowers*, I refuse to answer any further questions on the grounds that it may incriminate me (and my friends swore me to secrecy).

I was also thinking about asking my friend's son. I met him when he was about twelve or so. His Mom invited me to stay with them when I took a temporary job at the Kamloop's Art Gallery. His Mom and my partner are my Powers of Attorney. I made all these plans for my death. Some of them are definitely valid; everybody should have legal documents drawn up. Otherwise, you and your belongings could become government property. We've all seen what they've done with the national debt—they've been able to manage that pretty well! We have a responsibility to take care of ourselves even in death.

Are you angry about being HIV positive?

I used to be. I used to blame the person who infected me. I blamed it on my drinking and on the drugs that I used to do. I blamed it on whomever I could. I hated the fact that my life was over, at least from what I could see. When I was diagnosed, there were little or no services for Aboriginal people living with HIV and AIDS. There were organizations that did educational workshops on prevention, but when it came to dealing with the virus, the medications, my family and friends, there was nothing. Nobody tells you about all the psychological challenges that you have to deal with. Yes, I was angry about becoming HIV positive. For awhile I asked myself, "Why me? What did I do to deserve this?" I was angry about the lack of services available, as well as the lack of response from Aboriginal leadership in regards to the Aboriginal HIV/AIDS epidemic.

So, what did you do?

At first I made statements at conferences and other public meetings about HIV and AIDS. I asked why nobody was doing anything about Aboriginal people who lived with HIV and AIDS. I learned as much as I could and applied for a job with Healing Our Spirit: BC First Nations AIDS Society. I started out as a Peer Support Worker, trying to help other Aboriginal people learn how to live with HIV and AIDS. I tried to help everybody I could. It was a great experience. I saw a lot of very angry people who just wanted somebody to do something. I learned more about myself from these other people living with HIV and AIDS than I ever had before. I definitely learned what true patience is and what a real virtue it is. I understand the diversity of the Aboriginal community and our issues. I recognize coping mechanisms and understand why people use them. I have learned more about acceptance of myself as well as everybody else.

How did you deal with your diagnosis in the beginning?

I didn't deal with it. It was easier at that time to hide everything. It seemed harder after I started telling people, like family and friends; they took it pretty hard, as you can well expect. One of the things that I wasn't expecting was the self-imposed exile and the feeling of constant judgment. I can honestly say that everything that I was doing or had recently done was being judged. Maybe I have been the hardest judge of myself, even more than the people who I was blaming for the judgment. Whether it was my Mom, sisters or brothers, I felt that they were always watching me. If I sneezed, coughed, stayed up to late, got a cold or anything, they would be hovering over me, ready to hand me a tissue, give me a cough drop or send me to bed. I got sick of that pretty fast. I stopped telling them anything, not that I told them anything much in the first place. I had some of the answers for myself but was afraid that what I would have to tell them would get blown out of proportion.

It reminds me of a story I once told at a conference about being a spider. The Spider sits on his freshly woven web, tentacles running off to his friends, family members, doctor and such. Spider wasn't even sure where some of the tentacles went or why. One day Spider sneezes, and in an instant, everybody surrounds him. His Mom and Dad, his sisters and brothers, and somebody he didn't even recognize. Everybody else around him looks at him and expects him to start cracking up, to break or to drop dead or something. Wow, that was weird! Spider learns after catching a cold that it is too much like work making everybody think everything is okay. It was too much like work to answer all their questions. Spider learned that it would be easier to just sit still and act like everything was just right. Everything is just perfect. Denial was easier to live with than to accept the disease and the dis-ease that everybody was in, including Spider. So Spider kept very still, trying very hard to make sure that his web didn't shake, not a shimmy, no quakes and no surprises, which is just what the disease wants: to be denied and left to its own devices. For about five years, this denial was just so: no real questions, no real answers, no real living going on, except for the virus which flourished.

How do you deal with your diagnosis now?

I am more realistic. I have medications to take in the morning and at night. It's hard sometimes not to miss doses, but every now and then, I do. This missing is bad according to the doctors. One thing which was the hardest thing about starting this medication, was accepting the idea that once I started these treatments, I would never be able to stop, unless of course, they stop working. This ineffectiveness could happen if the virus

becomes immune to the medication. We don't want that to happen, so I try to take them as regularly as possible.

The medications, like everything in life, have their effects on my physical, spiritual, emotional and mental well-being. In order for the drugs to be as effective as possible, I have to accept them mentally. In my mind, I tell myself that the treatments are good and beneficial. I also use my mind to remind myself to take the drugs. I mentally try to block out the negative connotations of the therapy.

My spirituality allows me to take the medications. Although they are not traditional medications and are, in fact, foreign substances of a chemical nature, they are a part of my spirituality. I pray that they are working and that I will not develop a resistance to them. I pray that they will keep me alive until there is a cure. I know that if I don't take the medications, I will be overrun by HIV.

When I do become overrun with the virus, my immune system slowly starts to break down, and I become depressed very easily. I lose some of the fight, which is mental. My response to almost everything around me becomes very emotional. I sense the anger rising in me because I feel helpless. Inside I'm screaming and outside, I become a Spider again.

When I take the medications, everything seems to even out. I can deal with my emotional self, and my response is, in fact, more level. My physical being becomes closer to the person who I want to be. I don't look sick or tired. I don't look as skinny. I hate it when people walk up to me and say how slim I look—maybe I have tapeworms, and it is none of your business. It gets hard because at that point I am usually feeling run down and emotional and tend to get mad.

I have my good days, and I definitely have my bad days. I almost don't smoke. Every now and then, I feel like lighting up. I usually have a pack with me. I like to smoke when I'm in the car on a long drive to kill a little time, and a little bit of myself, I guess. I know that is a bad thing to say. My doctor says that everything is fine in moderation. Smoking for me is a coping mechanism for dealing with some of the stress of work and of this disease. One thing nobody tells you is that learning to live with HIV is a lot of work. It's more than a full time job.

Do you have supports?

You mean like panty hose?

No, sorry, I mean do you have a support system of some kind?

I know what you mean. It was just getting so serious here. I definitely talk more to my family and friends now than I ever did. I still

don't tell them everything, which is more for their benefit than mine. I have a couple of really close friends and my partner who know pretty much everything. I just don't let them talk to each other.

Are you afraid?

I've never not been afraid. Sometimes I look at death as a part of life. Most of the time I still ask "Why?" One of my biggest fears is that I have to cram the rest of my life into a small amount of time. That scares me and makes me mad. I have a lot of nieces and nephews whom I adore, and I am afraid for them. I am afraid for the three Godchildren that I have. I am always afraid that this Christmas is the last Christmas, the last New Year's Eve, my last birthday. I was afraid that I'd never see my thirtieth birthday, but I did. I was afraid I'd never see the end of this century, but now I have. I'm not afraid of death itself; I'm afraid I'll miss something, like the day they find a cure for AIDS.

Do you have any friends?

I have a lot of friends, most of whom I take for granted. It is hard for me to show my appreciation to everybody because I usually over do it. My worst habit is that if somebody likes something that I have, I usually give it to them. That is a really bad habit. I have to grow out of it. I have lost some of my friends along the way, when they found out that I am HIV positive. They weren't true friends though; just along for the ride.

Do you have any family close by?

They are never more than a phone call away.

How is your partner taking this?

He is taking it a hell of a lot better than most people would. He lost his best friend when we first met. He had no idea about me. One night I told him he could ask me any one question he wanted to ask. After a while, he just said that he already had an idea that I was HIV positive.

How has your HIV status affected your intimate life?

My partner is negative, and I am positive. We are what they call sero-discordant. Ultimately, I will never do anything that puts him at risk of contracting this virus. I'm more touchy-feely than he is, so I guess for him it's not too big of a deal. For me, it's hard to say. Some things just aren't as important as they used to be. Now, that's a sign of old age isn't it! Yeah, sex just isn't what it used to be so I gave it up...!

Do you have a plan for if you become ill?

Yeah, I'm going to milk it for all its worth.

Day to day, how do you feel physically?

Pretty good. I have a hard time getting up out of bed and starting my day. I should probably go to bed earlier. I don't suffer from fatigue at work, but I usually take a nap at home in the evening. Physically, I have no complaints. I have the occasional headache, a side effect from the drugs but nothing that I can't handle so far.

What medications are you taking?

I take Ritonavir gel capsules and Crixivan. Ritonavir is also available in liquid form that you pour into little gel capsules yourself. The major problem for me was the flavor and the smell of the liquid medication. It got so bad last summer that I couldn't swallow them at all. That was really gross. So, my doctor requested that I have special access to a gel capsule form which is easier to take. You can't really taste it, and my doctor says that it works very well with the Crixivan, also known as Indinivir, both of which are called protease inhibitors. I take them in combination with Lamivudine, also known as 3TC. In the United States, it's known as Epivir. The other drug in my combination is Stavudine. Like all the other drugs used in the fight against the virus, I think it has issues - complex identity issues. Anyway, Stavudine is also known as D4T or Zerit. I don't know why they give these drugs so many names. 3TC and D4T are classified as reverse transcriptase inhibitors.

Just in case you are still following me, I take two capsules of the Crixivan, and one of each of the other three drugs twice a day. I also take a prophylaxis drug called Septra. Not to be left out, it is also known as Bactrim. Chemically it is called Trimethoprim-sulfamethoxazole. It is an antibiotic used to fight off pneumonia called pneumocystis pneumonia.

There are other prophylaxis therapies which help prevent other opportunistic infections.

How much do the medications cost?

The Ritonavir is covered under the Special Access Program, which I believe is supported by the drug company which makes it. I don't know how much it costs. The other drugs cost about seventeen hundred dollars a month. The Medical Services Plan covers the Sulfatrim.

Who pays for the medications?

The BC Centre covers the HIV drugs for Excellence in HIV/AIDS at St. Paul's Hospital. They dispense the medications from a pharmacy right at the hospital. In the US, the medications can be mailed right to your home. The St. Paul's Hospital assists patients in handling some of the side effects. They keep files on all the patients. My doctor picks up my medications for me. The reason he does is that on one occasion my prescription was changed without consulting my doctor or me. So, now, he picks them up, and I pick them up from him whenever it is convenient for me.

Is access to treatment a problem?

The only problem that I've had is having a busy schedule. I work full time and volunteer a lot. I spend a lot of time on the road, in the air and in hotels. My current schedule has me booked almost all the way up to July, even though this year has just started. Accessing the therapies or drugs is hard if you are constantly on the go, and you have to book a month in advance for an appointment at the pharmacy. Basically, the drugs are there if you want to take them. The drug therapies aren't for everybody. Some people can't handle the side effects. Some people can't handle the strict regimen. Some people choose not to be on the drugs. For me, the major problem with accessing the drugs is taking them for granted. Nobody has ever told me that I can't have them, so if they weren't there, or if I couldn't get them anymore, that would be a problem.

Do you face discrimination because you are a Two-Spirit person?

Not really. There are some very great Two-Spirit people who have walked this path before me. People like Art Zoccole, Dr. Terry Tafoya, Naz Therriault. Their courage in sharing their stories and teachings about Two-Spirit people has helped me understand who I am. Being a Two-Spirit man is so much more spiritual than sexual. The gift of being a Two-Spirit man

means that I have a purpose. A part of my purpose involves my day to day living, some of it is in the work that I do, both paid and as a volunteer. As people, we never stop growing mentally and spiritually because we always have something to learn or we always have something that we can teach to someone else. I believe that I can only be discriminated against if I allow myself to be.

What about discrimination because you are HIV positive?

That would be illegal. The United States discriminates against people living with HIV/AIDS by not allowing them into the country. Here, I am just as free as everybody else to do what I want, when I want and how I want to do it. The only difference between now and that age when you think "If I only knew then, what I know now" is that I can afford to do all the things I want to. I've become the person I used to envy. I can take long vacations wherever I want to, whenever I want to. Then, I get to be discriminating. After all, I'm a Two-Spirit person, born with good taste and an amazing sense of myself and my own personal style.

As I said before, some people don't talk to me anymore. They were never really my friends, and I consider it their loss. If they ever need me, I'll be here for them.

Are you on a special diet or an exercise program?

No, I haven't changed anything since I've become positive. I try harder to eat better foods. I have a high metabolism, so it is hard to gain weight. I have set a goal to gain about twenty-five pounds this year. I have a list of things to do in 2000; one of them is to exercise more regularly. I try to drink only bottled water. Caffeine isn't good for me, so I try to limit my intake. I try to have vegetables and fruits in the house and juices and cereals. It's hard work to eat breakfast, anything more than coffee. Breakfast is always a challenge for me. On weekends, my partner and I have breakfast together. There's nothing special about my diet. I guess I am afraid that I would make diet too big of deal, and I could never afford it longterm, especially if I got sick.

Exercise? I have roller blades and want to buy a bike. I should walk more than I do. Maybe I'll take up jogging or running cross-country. I've always wanted to do a triathlon, but that would get really expensive really fast: bike, shoes, running shoes, swim suit, goggles, running shorts, bottles of water. See, too expensive already, and I haven't even started.

What keeps you going?

There was this one time when I was having a hard time. I was drinking too much and not taking care of myself; my job was really stressful, and I just wanted to give up. My doctor and I were discussing what it was that made my life what it is. One of the things he asked me was, "What do you want to live for?" I didn't answer him just then. He referred me to a therapist who wanted me to join an AA group, to go to just one meeting. I couldn't do it. I couldn't go to a meeting because of my on-going difference with the Church. I appreciate the sentiment of the Serenity Prayer, I just can't pray to God. So, I stopped going there, to the therapist. I never did go to an AA meeting.

All I could think about was what my doctor had asked me. "What do you want to live for?" After about three weeks, I went back to him with what I thought was a great answer. I reminded him of the question and told him that I didn't know what I wanted to live for, but I knew that I didn't want to live like this. That was about a year ago. I swore I would give up the stressful job, which is on my 'List of Things to Do in 2000'.

I want to finish a children's book I've been working on. I want to finish a couple soapstone pieces that I started a long time ago. I promised myself that I would learn to play guitar, take voice lessons and sing in front of anybody who is willing to listen. I also want to start an acting/modeling portfolio. One of these days I will have my own studio and/or gallery. That's what I want to live for.

What do you see as missing in Aboriginal HIV/AIDS work today?

There were no long-term survivors when I was newly diagnosed. We need more Aboriginal people who have survived with this virus to tell their stories. We need them to advise newly diagnosed people about the challenges of learning to live with the virus. There is a big difference between a 'newly diagnosed' person and a 'newly dealing with' person. It took me six years to realize that I had never really dealt with my diagnosis of HIV. I didn't start living with this virus until the last two or three years, so I guess, I am 'newly dealing with' my HIV.

We need to teach about the gifts of life including Two-Spirit people and how they have worked to become leaders in the fight against the spread of this virus.

We need to learn more about how to celebrate the diversity of our Aboriginal communities.

We need to teach about two different gifts - the first being HIV and the second being AIDS. This disease is so complex; we need to break it down a little so that it's not so much to absorb.

We need to teach responsibility. It is easy for us to say the leadership isn't doing anything. That takes some of the focus away from the work we could be doing on our families, our organizations, our communities and ourselves.

We need to teach more about the fact that HIV is preventable and that HIV disease is treatable. The cure for AIDS is stopping the spread of HIV.

Do you have any final comments?

Living with HIV is the hardest thing that I have ever done. It has been the most rewarding in regards to the friends I have found because I'm living with HIV. I have learned respect for myself, which makes it so much easier for other people to respect me. I have no limits on my life anymore, and so I should have no regrets. Living is easy; living without regrets is a challenge. I have learned to lead; I know when to follow, and I know when to get out of the way. I have learned that the only thing constant in this life is change and that's that.

Kukstemc, le 7 enc tu!

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