

“HIV in My Day” - Interview 71

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Interviewee: Anonymous (X); Interviewer: Ben Klassen (BK)

Ben Klassen: Great, thanks so much for being here—

Anonymous: Yeah thank you for having me.

BK: --with us and agreeing to share your story with me. Just to get started, can you tell me a little bit about your connection to Vancouver?

X: Well I was born here. So I have a connection all my whole life.

BK: And you've lived here?

X: I lived here fifty—fifty-six years.

BK: Wow.

X: Yeah. I grew up in South Van. Well I grew up in the east end until I was a teenager and then we moved to south Van. So I grew up Champlain area. And uhm, I was diagnosed uhm, well I got into the drug scene. So I had to do what I had to do to get money. And somehow I contacted the virus and it was a real—a real—it was really hard years ago. It was a real epidemic. People uhm--I remember being in the lineup and people whispering about me, oh she's the one that's HIV, she's the one that's HIV. And it was terrible, it was god awful. I went over to my friend's place and uhm—actually my boyfriend. And his-his—he was HIV too, though, not from—from years ago and anyways he went to visit his mother. I'll just tell you a little bit about that. And he had a spoonful of ice cream, and his mother just got livid. Oh my god how dare you put the spoon—put the spoon into and take another bite. It was just—it-it was really, really—it was terrible. And uhm, I don't know what to say. It was really hard back then though, it was—it was like the plague. You know people—it was a lot different. Nowadays people accept it a lot more. Years ago it was such an isolated illness, and it probably still is. I've been very fortunate, I've been very uhm—I never got sick. I was—I guess you get run down and stuff, but I never really got sick. And I didn't have to take the medication for a lot of years. So I was really, really lucky. Uhm, I don't know what to say. Ask me—

BK: Yeah no, I can definitely ask you some more questions. Uhm, do you remember—where did you first hear about HIV?

X: I heard it on tv. Never did I think I would be diagnosed with it. It was actually—I was in a recovery house and everyone had to take a test that was just the—that was the house rule so, never did I think that I would be tested and I uhm, I got a phone call from my-my-my doctor phoned my mom and told my mom that I was—had come to the office to see him because I had taken off—taken off from—let me back up a bit. I uhm—I had to—through uhm, jail I had to go to a recovery house. That’s how I found out. And uhm, it was for soliciting, it was nothing serious. And I uhm—it brings up a lot of memories. Could we stop this for a sec?

BK: Yep.

X: Sorry I’m going back and forth.

[tape cuts out]

BK: So did you—you know, when you were diagnosed—did you have any support available to you?

X: I had no support. I had no support. I fell off a roof, uhm about seven years, or ten years after my diagnose—I had my family doc, but my family doctor didn’t know much about it. I think I was probably his only—his first case. So he didn’t know much about it, but then I had a bad accident. And uhm, I was at St. Paul’s hospital and they-they introduced me to a specialist. So I went. And then for the last twenty years I’ve seen a specialist. Which wa—he was wonderful, he gave me so much support, which I had no support the first seven to ten years. Nothing. My mother—my mother was fantastic, my mother always supported me. But I mean, to know more about it and stuff, so I read books I read everything. It’s like night and day I think from people being diagnosed years ago, then people being diagnosed now. I think it’s a lot more accept—accept—you’re accept, more accepted now. Before you were the plague, oh my god people wouldn’t even touch you. Like even—like if they bumped into you they would think that they were going to get sick. It was really, really uhm, people were really ignorant about it, right?

BK: And now you have more of a community of support?

X: Oh now I have a community of support and know a lot of people that I associate with are—that’s what—I mean they were diagnosed and stuff and they live with the illness.

BK: And where is that community, where do you find that community?

X: In the West End. Doctor Peter Centre. It’s a wonderful organization. And they’ve really supported me there. They have good meals, because nutrition’s really uhm, really essential with

HIV and so they—you know they, have really good uhm, really good workers there if you want to talk to them and stuff. So they've really helped me, through the years.

BK: How long have you been going there for?

X: Twenty years.

BK: Doctor Peter's Centre, wow.

X: I was the first girl there. I don't want that part—

BK: Well that must've been an experience.

X: It was an experience, yes. Yeah it was all men, I was the only woman that was there. It was uhm, it was really, you had to get along with men to be the only girl there and feel okay about it, right.

BK: Were there are lot of gay men that were going there at the time?

X: They were all gay men.

BK: Okay.

X: Pretty well, there was the odd one that wasn't. I'd say out of ten, there'd be maybe one that wasn't. And that's when they said it was a gay—HIV was with the gay community, it's with the heterosexuals, with any part, it doesn't matter what you are, you can still get this disease right. It's got no names on it, right?

BK: But I guess back then people thought it was a gay disease.

X: Back then people thought it was a gay disease, yep. And how—that's so un—that's just so not true, right. And heterosexuals were getting diagno—well drug addicts and stuff were getting it. And I think that's—took a lot of years before they didn't consider it the gay disease, right.

BK: Do you think that's changed a little bit now?

X: Oh yes, very much so. There's been so many diagnoses, right? And well I-I'm sure there was a lot more diagnosis back in the day but people were too scared to get diagnosed, right? Being if you're a drug addict or whatever, right? You're scared to know. But as long as you have

like good nutrition and stuff and I was really lucky, my counts were very high. My health counts and stuff were very high so—I didn't need medication for a lot of years, which was really good because a lot of people that I know, there was about fifty of us that started, and there's only four of us left. Everyone's dead. And uhm—yes it's sad—I just lost someone last week—it's sad because you know, you get to be friends with people and then all a sudden they die off. But years—years ago—[inaudible 09:34]. No it's not considered a gay disease anymore like I said, so many people that are heterosexual and that are into the drug scene that are into the fast life scene, can get it right.

BK: When did you start on meds?

X: About ten years ago.

BK: And what was that like?

X: Oh that's what I was talking about. I've got uhm—well the medication was okay for me but if I would've started on the meds years ago, that's why a lot of people were dead, is because they were given too much AZT and they didn't know how much to give. Because that was the only drug available many years ago. So they were killing people trying to help them. So that's what saved my life too, being on meds later on in life.

BK: And you were kind of aware of the fact that some of those meds back in the day were really hard?

X: No I didn't know then.

BK: Oh okay.

X: No I didn't know then, but looking back now. Now I remember reading how AZT killed a lot of people when they thought they were helping them. But they didn't know any—they didn't know what to do. It was really hard.

BK: And when you started on the meds they—did you have any side effects?

X: I had no side effects. I'm still on the same one that I started with. Which you have different cocktails, and I'm on the same one still. Yeah.

BK: Before going on meds, how were you looking after your health at the time? Were you doing anything to try to look after yourself?

X: Yeah I was—try and fight off, fight the drugs and stuff, right? Try not to do drugs. And uh, I quit needles, and just tried looking after myself more. There's a lot of side effects with a lot of the medication but I was fortunate I didn't have any side effects.

BK: Did you know many positive women back then?

X: I didn't know any. Didn't know any. It was very isolated. Yeah. Until it—well actually, I shouldn't say any. I knew a couple, a couple of women. But they're not here now.

BK: As time's gone on, have you managed to connect with more women who are HIV positive?

X: Yes I have. Yeah, I have. I have and you know, it doesn't have to be a—it's not a death sentence, and that's what you think it was years ago. It was like a death sentence. And now it's—you know if you get tested you can live just like a normal—a normal life.

BK: Do you remember when that kind of came—you realized that, that it wasn't a death sentence anymore?

X: Uhm, well I-I thought for sure like the first ten years I was just waiting to die. So probably the last ten years or so, I know it's you know, as long as you eat well—eat good, and stay out of mischief right, so to speak, then you can stay alive. It'll always be hard, you know you always feel like you have a plague. Even having the disease, you know like, years ago it was a lot worse, but you still feel it inside. You still feel—you feel dirty right.

BK: So there's still like, stigma.

X: Just to myself I think, you just—you always just don't feel the same. I don't know, I don't know how to explain that. But—it's a lot better to be diagnosed this day and age because you're accepted a lot better, and the medication's a lot better. It's not killing you, it's helping you.

BK: Besides your doctor back then, when you started seeing the specialist, was there any other places where you were getting information about you know, your health and HIV?

X: Uhm, AIDS Vancouver.

BK: Okay.

X: Yeah, AIDS Vancouver were really good too. I found out a lot of information, and I just read a lot of literature and stuff. That I was going to be okay and that I wasn't alone.

BK: So you actually went to the—to AIDS Vancouver.

X: I did, I did. I did everything I could to learn as much as I could about it. And uhm, I went through counselling and stuff. Because it's terrible to be isolated and not know what's going to happen tomorrow.

BK: You must've been one of the only women there too, I imagine in the early years.

X: I was. I was the only woman. There was a couple women that came after me. But yeah, it seemed like there wasn't that many women that—that kind of so to speak came out of the closet about it, right. But when you're just first diagnosed it's just what a terrible feeling. The worst feeling ever. You feel like you have terminal cancer, right.

BK: And yet you're still here.

X: And I'm still here, yeah.

BK: That's a lot of resilience.

X: Yes I do, yeah. That's for sure.

BK: Uhm, do you have uh, yeah any other thoughts about how your interaction with the medical system has been through all of this?

X: I don't understand.

BK: Like doctors and—

X: I just pretty well saw my specialist, so I didn't really have that much contact. Oh I, my family doctor there was a lot of ignorance about—I wouldn't say ignorance but, he just said oh you know I don't know much about it, I don't know much about it. And he's a doctor. You know—he didn't even—he told me I had to see specialist but he never gave me any help, you know any names to go see anyone. He was just like—didn't know much about it. Years ago people they—they weren't uhm, educating themselves about it, when they went to school. That's about it.

BK: So that's why you got referred to a specialist.

X: That's right.

BK: Yes. Uhm.

X: So, that's my story.

BK: Yeah, I think we've covered a lot of the questions that we tend to ask. Uhm, do you have any advice for younger folks who are around today, as somebody who's you know lived with this for many years?

X: Get in touch with Doctor Peter Centre or get in touch with a counsellor or someone that knows how to direct you to the right people because it's—it's not a—it shouldn't be a lonely disease, you know. You can live with it and you can live normal.

BK: So find support.

X: Find support.

BK: Find community.

X: Community and support. Vancouver's the best place to have it, for sure. Like my-my boyfriend he was from a small town—I'll just finish this—from a small town and he said his family didn't even want him to come and visit because—because they were scared that they'd find out that he had it. That's how bad it was. Yeah, just find support and there's a lot of support out there for women, or for males. There's a lot of support out there. Don't give up, because it's not a death sentence. It's like having a cold now. Except it doesn't really go away. But now the medication's so good you're undetectable, and what that means is you can't pass it on. So that's how—that's how the meds are changed from years ago, right.

BK: Yeah that's pretty amazing.

X: It's really amazing, yeah. You know a lot about it right?

BK: I know a little bit, yeah.

X: I bet you know a lot.

BK: That to me is just—

X: That is just—I know, it’s just amazing. But they shouldn’t, you know uhm—you’re undetectable but you gotta keep up with the bloodwork, right. I mean that’s really essential, because that’ll tell you where you’re—just because you’re undetectable today, if you don’t take your medication, doesn’t mean you’re going to be undetectable, so you still gotta be careful. You just always take your medication right.

BK: Has been something that you’ve found challenging? Or is that—

X: I have, I have because my memory’s really bad now. And so uhm, they give me the medication so I don’t forget. So I—at Doctor Peter’s Centre they’re really good that way.

BK: And I guess—so you live in the West End now?

X: I lived in the West End for the last fifteen years. I love the West End. It’s nice that I get affordable housing right, otherwise it’s so expensive to live out in the West End. Do you live in the West End too?

BK: No I wish.

X: It’s expensive.

BK: It’s expensive. But it is sure a beautiful place to live.

X: Oh it is, I love it. And walking distance to everything. You know you don’t need a car. Because all my appointments, everything. Shopping, Safeway, well independent now. Groceries, everything is all walking distance. It’s like a little town right, but still like, the big city.

BK: So it sounds like maybe that’s been a big part of your like, survival strategy too?

X: It has yes, the West End yes. It sure has.

BK: Your resilience. Uhm, I don’t have a whole lot of other questions to ask, but we always like to leave some room just to you know, let you add anything that we haven’t touched on.

X: No I think we covered everything.

BK: Yeah I don't want to dig too deep into any of this stuff if it's going to be too challenging, so I think this is great.

X: Thank you.

BK: And thank you so much for sharing all of this.

X: Yes, thank you.

BK: So I'm just going to stop this for now.