“HIV in My Day” – Victoria Interview 18

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Interviewee: Claude Heneault (CH); Interviewer: Art Holbrook (AH), Charlene Anderson (CA)

Claude Heneault: Okay, what I’ll do is I’ll talk to you and not the camera.

Art Holbrook: Yeah, yeah. So, just a little background—how long have you lived in Victoria?

CH: Twenty years.

AH: Twenty years, okay. How have things changed here in that time?

CH: What’s changed?

AH: Yeah.

CH: Oh, the face of HIV. ‘Cause it used to be mostly gay people, and now it’s mostly drug users.

AH: Yes.

CH: I wonder where all the gay people went. But I—not that I wonder just, maybe they died, or maybe they just don’t like to come to AVI because of the street—annoying drug users, because some are annoying.

AH: I’ve heard both those answers. Yeah. But how has the city changed in that time?

CH: Uh, the city hasn’t changed, I don’t think, except well—about, are you talking about drugs? Because the city has changed.

AH: No, just in general, the city.

CH: Well, it seems like there’s a lot more homeless, and a lot more drug users. Out in the plain—out in plain view.

AH: Well that’s interesting, yeah.

CH: I think because they’re homeless. I don’t know why, or maybe they come here from Vancouver, I don’t know. There is definitely a lot more new faces of drug users, and they look like they have HIV.

AH: So, when did you first hear about HIV/AIDS?

CH: Oh, in the eighties I heard about it, but it didn't affect me. I lived in Penticton and we didn't have AIDS there. And then there was a guy who had AIDS in Penticton, yeah. And that's all I knew about AIDS. I didn't know anything about AIDS.

AH: So, your initial reaction was – you weren't worried about it or what?

CH: No, 'cause I'm—no, I wasn't worried about it.

AH: Because you were—no one's gonna, in Penticton's gonna have any trouble so…? Well, what happened when that first person showed up with it?

CH: I was concerned. I was afraid to share the same power tools. 'Cause we worked at the same place, and we shared some of the same power tools and I was afraid that maybe, what if he bleeds. Oh, by the way, he didn't have HIV, it was his mom that had HIV, and I was scared to share the same chainsaw, because when we file it sharp, when you sharpen the chainsaw, I was afraid that he had caught it from his mom, and then his HIV would be on the file, and then we share the same file, the same saw, the same file. So, sometimes he'd sharpen it, sometimes I'd sharpen it, and I was a bit concerned. Because his mom had HIV, so he has to have—I was afraid of HIV.

AH: Yeah, that's interesting. So, how did you learn more about the disease? You must've gotten past worrying about the file.

CH: In 19—this was in '88, the file, chainsaws—now in 1996, eight years later, I went to VIDUS—Vancouver—VIDUS, it's an acronym, Vancouver Injection Drug Users, and they were giving us a twenty dollar bill to test, anybody that had needle tracks—as I had needle tracks—a twenty dollar bill just to get tested, and then five days, you go back and they give you another twenty dollar bill to tell you the results. Whether it's positive or not positive, you still get the twenty. So, I went there, I got my twenty dollars, got tested, five days later, I went back, got another twenty dollars. And they said I was HIV positive, which didn't surprise me, because I had been sharing needles for maybe ten years in East Van and other places. So, when she told me I had HIV, it didn't affect me at all, because I thought I had it.

AH: I see. So, was there information that you could look to? Did you do anything about researching the disease and understanding it more when you found out you were positive?

CH: Oh yeah, I went to that AIDS Vancouver where they're very nice and they told me all sorts of stuff that I can do, or that maybe I shouldn't do. And I took their advice, little things to keep healthier. Like sleep when you're tired, or if you're hungry, eat – things that normal people do that us drugs addicts, sometimes we forget. And sleep when you're tired – instead of going to sleep, it's just try more drugs, and this is hard on the system. So, I do everything I can to maintain health, stay healthy. So, I did quit drugs, eventually, I quit poking my arms.

AH: So, you responded to the information that you got?

CH: Yeah, to the information.

AH: So, was that information adequate? Did you get what you needed, or were there still questions?

CH: Well, all the things that I shouldn't do, I listened, I believe it. But there's things I didn't listen to them. They told me to take AZT – I said no, because I had heard that AZT kills people. AZT was meant for cancer, and it didn't work for cancer, and now they're trying it on people who are HIV. I said no. My doctor tried to get me on AZT – I said no, no. It took me six years to finally get on medication because I didn't want any meds. I said, "I want to wait until I'm sick, until I really know that I have AIDS, 'cause right now it's just HIV positive. I'm gonna wait 'till I'm full-blown, then there might be some better meds." And it worked out, it worked out. I waited six years and they came out with really good meds, and they do not prescribe AZT. And if I had taken that AZT in '96, I probably wouldn't be here, 'cause it's very hard on the system.

AH: Yeah, we've heard that.

CH: I'm really happy with the new meds.

AH: So, what meds did you wind up getting?

CH: Oh, D4--D4T, T3C—not DDI, but another one. These are just acronyms to me. Now, I'm on the meds that the words are just too long.

AH: So, you talked about your behaviour changing. Did your sex life change?

CH: Yeah, yeah. I quit going to the bars and dancing, and meeting strange women that I just go have sex 'cause we're drunk after dancing in the bar. I quit going to the bars, I quit dancing. I quit socializing a lot.

AH: Did you become kind of isolated at that point?

CH: Yeah.

AH: So, you've mentioned a couple other things. Anything else in your behaviour that was changed? You've cut out the—

CH: I became a bit careless, and getting in risky activities like dangerous cycling or rock climbing, like I didn't care about death anymore. Like, I did things that are dangerous, like rock climbing with no ropes, and you go, oh well, if I die, it's okay. It's probably going to be easier to die anyways.

AH: So, you gave up on the women but you—

CH: Because I don't want to affect others.

AH: Okay.

CH: It was just ‘cause of my conscience, because at the time, I believed in karma and I believe that if I—like I believe that if I do something wrong, it’s bad, my conscience going to be eating me away. Yeah, so there’s things I don’t do, only because of the conscience and the karma thing.

AH: That’s good of you.

Charlene Anderson: I have a question. When you went to VIDUS, did they have counselling for you when they gave you the diagnosis?

CH: No.

CA: What did they say—go to AIDS Vancouver or…? That’s all they say?

CH: A whole list of places a person can go, so they direct us to places but they don’t—I don’t think they do counselling.

CA: They didn’t sit and talk to you and say don’t do this, don’t do that, until you talked to somebody else, they just—

CH: Yeah, they told me there’s counsellors at different societies, AIDS Vancouver mainly, there’s other places in Vancouver, too.

AH: So, when did you come to Victoria?

CH: ‘96—‘97.

AH: ‘97. So, did any aspects of who you are shape the way you experienced the epidemic? The examples they give here are race, class, gender, education, employment status, sexual orientation, etcetera—any of those things influence how you responded? And I think you already said something—

CH: Yeah, oh yeah. Like I can’t—I don’t want to be a roommate again. I used to read the papers, say “roommate wanted.” Well, now I skip that, because I don’t want to move into someone’s house and then he finds out I got HIV and then he gets angry, or he gets scared. So, I always tell people now I that have HIV. I tell them pretty quick. Soon as they start asking questions, I tell ‘em I got HIV. They say, “Oh, how come you don’t work?” “Oh, I got AIDS.” That fast.

AH: Okay, well, I think this question’s pretty well answered here, talking about how the epidemic changed your personal life. Did this—this interview guide that they put out for us jumps to another question: was the government’s response?

CH: They don’t care, they’re busy people. Maybe they’re busy in their offices, maybe they give us fundings, but me, the government, I don’t—nothing to do with me. The welfare worker didn’t say anything, they’re busy. I don’t know about the government. I know they fund us, and they help us, they give us meds, and give free meds.

AH: But at the time when you were first diagnosed?

CH: The government, oh, didn't get involved, no.

AH: I've never liked that question being there in the middle of talking about personal things, all of sudden it jumps to the government. And so how did you experience the public reaction to the epidemic?

CH: I was surprised to see the public, it's like they don't care. 'Cause I tell people when smoke a joint, when I was first diagnosed, I tell people, "Oh no, I got AIDS—can't share the joint. Oh, I gotta tell you before you touch my joint, oh, I got AIDS." Said, "I don't care, I don't care." People don't care. People aren't scared of AIDS like I thought they would be. Nobody's worried about AIDS I think.

AH: Did you ever experience any of the discrimination or stigma that came along?

CH: No, never. Well, only in prisons. But in prisons, people a little cuckoo. Yeah in prisons, you can't say you have HIV.

CA: Why?

CH: Well, you won't be allowed to touch anything, even reading the newspaper, they wouldn't let me read the newspaper because I licked my finger one time, to turn the page. I got three guys, I guess they were watching, three guys right away got off their chairs, "Hey! Fuck, Frenchie, you fucking lick your finger and you got Hepatitis C." They didn't know I had HIV, but they knew I had Hepatitis C. They thought you could catch hepatitis off a newspaper, because I licked my finger to turn the page. In jail, it's different, people are frustrated, opinionated, they're probably the one percent of society that doesn't function properly. So, I don't think we should use them as an example, because outside in the real world, I've never been mistreated for HIV.

AH: So, in the AIDS community – to start with, did you associate then with the AIDS community?

CH: Oh yes, started hanging out with people with HIV. Made new friends at the AIDS society places.

AH: So, what kind of actions did the community take?

CH: Some people say, "Take care of yourself, get off those needles." And stuff like that.

AH: But that was sort of organized, community response?

CH: Yeah.

AH: Was there a lot of fear in the community?

CH: Fear of my HIV? No, I don't think so.

AH: Fear of the epidemic in general?

CH: No.

AH: They kind of just rolled with it?

CH: Yeah, they're happy. They're happy crew at AIDS Vancouver, when I was there twenty years ago. And they're happy crew here at AIDS Vancouver Island.

AH: Did you witness cases of people being shunned?

CH: No.

AH: How about cases of people being caring and compassionate—the other side?

CH: Yeah, I get that more. Far more.

AH: Okay.

CA: Do you see people being caring and compassionate with each other—like not just with you—but with each other? And helping out with each other?

CH: Yeah, us that have HIV, I find we're nice to each other.

AH: Do you have any examples of that?

CH: Well, everyday when I go get lunch at AIDS Vancouver Island, people [say], "Hi, Claude, how are you doing? How're you? How's this? How's kids?"

AH: Just a welcoming atmosphere?

CH: Yeah.

AH: Have you participated in any community mobilization, or grassroots responses, any demonstrations or activities like that?

CH: I went to AIDS Walk—no, yeah—yeah, of course, I volunteered at the AIDS Walks a few times, and World AIDS Day, December 1st, I went to the walk too, holding a little red candle. But that's about it.

AH: So, any other ways you became involved in these kind of responses?

CH: I was volunteer receptionist, I volunteered in the kitchen. I wanted to get involved with the AIDS places.

AH: Did you have any social or health related experience before you became infected?

CH: No, I don't think so.

AH: Any other roles that you played in the community?

CH: In the AIDS community?

AH: Yeah.

CH: No, just volunteering. I always say yes when they say, "Do you want to volunteer doing this?" "Yeah." "Do you want to join the Board of Director." "Yeah." I always say yeah, yeah. And they like me on the board. I think it was maybe you that said I was a yes, "yes guy." When they go, "Anybody opposed?" I'm a "yes guy," 'cause I'm here to back up the other. The reason I was on the board was to back up the other people. Everybody in favour? I'm here to back you up.

AH: Right.

CH: Somebody called me a "yes guy."

AH: So, you were a member of AVI?

CH: A client.

AH: But you participated with them as a volunteer—

CH: As a receptionist.

AH: Receptionist. And we were talking before, you were on the VARCS Board at some point?

CH: Yeah, one two-year term on the Board of Trustees.

AH: And that was what?

CH: '99, somewhere around there.

AH: '96, '7, '99?

CH: '98, '99. '97, '98.

AH: Okay, yeah. Have you ever provided direct care for someone else with the disease?

CH: No.

AH: And have you ever had any severe problems with the disease, just physical manifestations?

CH: Yeah, I got thrush a few times, and I got pneumonia twice, shingles once.

AH: Was anybody caring for you during those episodes?

CH: Yeah, I got my family here.

AH: Okay, so your family stayed with you.

CH: Well, they drive me to the hospital, bring me beer in the hospital, bring me cigarettes because I can't afford to make money because I'm too sick. Yeah, I got a nice family.

AH: So, you didn't have any problems with your family? They were accepting of you when they found out you were HIV positive?

CH: Yeah.

AH: How did they respond?

CH: Well, they're sad. Sad. They thought I'd die. I told them, "We're all going to die, it's okay."

AH: So, how has the epidemic changed the community?

CH: Oh, I don't know how it's changed the community. You mean the people at large or the HIV?

AH: Well, start with the community at large, then go…

CH: Oh, I don't know if it has changed the community at large, but I know it's changed people when they get diagnosed. Often they want to better themselves so they can live longer, if they can better themselves. And the drug users can do something, is quit drugs. Whereas some other people, let's say, for example, gay people, there's not much they can change. Like they're not doing anything wrong, they carry on with their job and their lives and stuff.

AH: Do you feel as though AIDS damaged the community or made it stronger?

CH: The community at large?

AH: Well no, the AIDS community.

CH: Yeah, it made, it makes us, HIV people all be together and friends. Like gay people accepted the drug addict that I was, and me, I started having friends that were gay, which I had never had before—friends that were gay. And we don't care—I don't care if a person's gay, still my friend. So, that's how it maybe made things a bit bettr, made the gay people more accepted, I think. But I mean, not that I didn't accept gay, from Montreal and there's gay people everywhere, but for me to have friends and not to be embarrassed to be seen with gay people, or even go and have a beer with them at the gay bar, it's something I wouldn't have done before. But now, I've learned to accept, and I even studied how come they're gay and stuff and… there's all sorts of reasons why they're gay. Me, I thought it was – well, I won't get into that, I didn't know what it was, I thought it was a choice in life or they were born that way. But now I realize it's a hundred different reasons.

AH: So, you feel that there was a coming together of the community?

CH: Yeah, us with HIV attempt to, like you say, come together.

AH: So, how has your perspective on HIV changed over the years? You started out when there were no good drugs. Now we have good drugs. How has your perspective about…?

CH: I know that the government will no longer put you on disability because you have HIV. Now you're HIV, even the doctors will put you and say, don't work—in 1996, it was still, "Don't go back to work now. Stay home and rest. You got HIV." Well it's been twenty-two years, I'm still working. And, yeah.

AH: So, did you quit work back then?

CH: Oh yeah.

AH: But now you're back at work?

CH: Yeah, 'cause I realize I'm healthier than a lot of people my age and younger.

CA: So, what has your perspective—okay, so when you were first diagnosed, you had one thought about HIV. What's your thoughts about it now? Has it changed over the last twenty years?

CH: Totally. Now I realize that you can live with it and it's not the end of the world, there's more dangerous things. I think sometimes maybe riding a bicycle downtown might be more dangerous or driving at high speed's more dangerous. Drinking and driving's a lot more dangerous than having HIV.

CA: And what about passing… So, I'm back tracking here a little bit—so you at the beginning thought when you first found out about HIV and AIDS, you thought that you might be able to get it from the file. How did you find out that you couldn't, and the different ways that it could be passed and not passed, and did you teach people about that, that were in your life? How did you go about that?

CH: Well, it took me – it was years later when I got diagnosed with HIV, and I do tell people you can't catch AIDS from a towel. Because I shared a towel, I was a single parent, and I shared a towel with my daughter until she was nineteen. And sometimes her friends would say, "Don't use your dad's towel, don't drink out of your dad's cup, don't take a sip of your dad's beer." And me, I'd have to educate my kids' friends and say, "You can't catch it yet, unless you start punching me in the face. So, if you're mad at me just use a stick or something, don't start punching me."

AH: Might get a little blood on your knuckles.

CA: Well, that's pretty cool, you got to be a bit of a teacher.

CH: Well, I got three kids, and they got lots of friends.

AH: So, those kids, your kids' friends, are they getting educated and getting smarter about it?

CH: Oh, they learn they're not going to get HIV from me. They'd have to sleep with you maybe.

AH: Couple of good-looking younger ones there.

CH: My line is—my line was, "It's not like we're about to have sex, so don't worry about it. You're not gonna catch it from water cup or towel or toilet seat."

AH: So, do you have any thoughts about what health professionals could do better today? Any advice for health professionals?

CH: No, 'cause I take my advice from them. They're professional, they know what they're doing, and I listen to those professionals.

AH: Going back again to early days, what was your experience with doctors at that time?

CH: Well, the doctor that filled the piece of paper to put me on disability, he told me, "Why are you going on disability? Go to work. You might live another five years. Wouldn't you like to make money and travel?" I said no. I said, "No, I don't want to travel, I want to stay home with my family." "Ah, okay, but you can work." "I want to be on disability. I want you to fill that, for disability." He said, "Okay, if that's what you want, I'll do it." He wrote down that I couldn't engage steps, and that I had difficulty, physical problem, which was not true. So, doctor lied for me. And they often do. My new doctor here says, "You fill the paper," because it says, do I need bottled water? Yeah. Do you need vitamins? Yeah. And what's the other thing I need? High-protein diet, yeah. But in real, I don't need any of it. So, doctors do lie to the government, otherwise I'd fire the doctor and get another doctor that will sign. I don't tell them that to their face, but they know it. If one doctor doesn't fill the paper, I'll just go see another one.

AH: Did I tell you this is going to go on YouTube? [Laughs] Any thoughts about what politicians and legislators might do better than what they are doing, regarding the HIV world?

CH: No, I don't think they can do much better. I'm not an educated person, so I don't know what they can do, because I think they do a lot already by giving us free meds, whether we work or on welfare, we don't pay for these meds. They cost a lot of money, and it's the taxpayers, my neighbours, everybody's paying taxes. So, that's why I try to be nice to the community, because I know they're paying my welfare cheque, they're paying for my AIDS meds. Yeah.

AH: But that wasn't always the case. When the epidemic first came up, the politicians would never say the word, right? When – Vander Zalm back then?

CH: Oh, I didn't know that.

AH: Oh, okay. I'm not trying to put words in your mouth.

CH: Nah, go ahead, I didn't know that the government shun on it—is that it—or tried not to pay for the meds? Is that, no. They tried to give us AZT, maybe they're trying to kill us.

AH: I don't think they knew that AZT…

CH: No, they're nice. I get more on welfare than a person in a wheelchair, so I feel very fortunate to have a nice government. I love my government, by the way.

AH: So, looking back over your experience, do you have any advice for future generations who have not experienced the epidemic?

CH: No, advice?

AH: Well, safe sex, needles?

CH: No, I don't have any advice because they all know it. People know not to share needles. It's not like back in the seventies when I used to share needles, we didn't think you could catch anything.

AH: So, do you think that the broader community has remembered any of the lessons learned from the epidemic? It was pretty terrible time back then. People were dying left and right. Did the community learn anything?

CH: No, I don't think so. They've learned, but young people don't care. If they want to have sex, they have sex without condom. They do. They don't share needles anymore because everyone knows, but young people still have sex with no condom. I only have one son, but his girlfriend, his new girlfriend, she always pregnant. New girlfriend, another one pregnant. He gets all his girlfriends pregnant. So, obviously they're not using condom. And my daughters have two kids each too. Two kids each – I'm at seven grandkids now.

AH: So, is there anything else that you can think of that you'd like to talk about in regards to this?

CH: No, no, I can't think of anything, because I'm really happy with the medical system, how fast and how well they deal with it.

AH: Okay, well then, thank you very much.