“HIV in My Day” – Victoria Interview 11

February 22, 2019
Interviewee: David Phillips (DP); Interviewer: Art Holbrook (AH); Also present: Charlene Anderson

Charlene Anderson: It’s going. Yeah.

Art Holbrook: Okay.

CA: Just start.

AH: Speak. Go.

David Phillips: Speak, go. What shall I speak about?

AH: Yeah, so you know, this is how you do it. She’s just started on doing these interviews, I’ve been doing it for awhile.

DP: Speak.

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

DP: I was back home in Ontario, in Windsor, and I heard about this gay cancer, in Detroit on the radio. Me and my friends at the time were like, “What’s that?”

AH: So, how did you respond to that, when you first heard of that?

DP: Well, it sounded scary and absurd at the same time, I would say—a gay cancer?

AH: Right. So, did you set about learning more about it, or did you just reject it out of hand?

DP: No, no, not immediately. I think that we learned more about it a few years later than back east, out here on the west coast.

AH: So, you moved out here during that time, sort of shortly after you learned about it?

DP: No. I was sort of early twenties when I first heard about the gay cancer. And start educating myself about it around ‘85, ‘86.

AH: So, what kind of sources did you go to for information?

DP: Actually, I would be flying back and forth between Vancouver and Ontario and reading magazines on airplanes, and that’s when I first started reading about it.

AH: Oh yeah. So, you lived in the two places at the time?

DP: No, my family was back east, and I lived here, and I went—I commuted back and forth a lot.

AH: Right, okay. So aside from those magazines were there any other sources?

DP: Mmm, I got into a new relationship and my new partner was educating me about HIV, and getting HIV testing for us, you know, to be partners. And we both tested negative and we thought that we were good to go.

CA: When was that?

DP: It was 1986, when Expo 86 was happening in Vancouver.

AH: Well, funny we didn't run into each other there.

DP: Yeah.

AH: So, how did you respond when you learned about it? You mentioned that you and your partner sort of took tests, and you were learning about it but what other changes? Did you change your sexual habits, did things…?

DP: Well, we were in a new relationship and we weren't interested in other people at the time, I would say. And that relationship lasted for about four years.

AH: Mhm. So, did your social life change any during that time? Were you part of the gay scene?

DP: I was, yeah, I belonged to a few groups like Squares Across the Border, which was square dancing in Vancouver, Seattle, Portland, different groups moving around doing that. It was a lot of fun. Yeah.

AH: Right. You know the big question here on this list is how did your identity shape your experience of the epidemic?

DP: How did my identity shape the experience of the epidemic?

AH: Or any aspects of who you are shape the way you experienced it.

DP: I'm not clear.

AH: Being a gay man, presumably, is part of that.

DP: Yes, mhm.

AH: Gay man, family values, your job, like all the things that made you who you were? Did any of that change, because of the AIDS epidemic?

DP: Uhm, hmm. Good question.

CA: A biggie.

DP: Yeah. What I recall from that time was my partner and I testing, testing negative, thinking that we were safe. And then our friends were getting infected, and a lot of people were on—uh—trying drugs like AZT and not getting well. And—and uh, ultimately my entire generation of friends passed away.

AH: Yeah, mhm.

DP: And my partner and I got infected around the same time. It was October, and we moved to the island, because I just said we're going to do better in a small community like Victoria, than in a big city like Vancouver. So, we moved over here.

AH: So, what did happen when you discovered you were infected?

DP: Well I just—it was like I—I had a intuition or something it's just I felt like I—that I was—that I had been infected. And I went to my doctor and uhm, I tested negative probably four or five times before I got, uh, you know a protein happening. And they recorded my seroconversion, they thought maybe they'd be able to help find some answers later.

AH: So how did things change when that happened?

DP: Hmm… Well it wasn't too long after that we moved to the island. And I was working for White Spot, and I transferred to a White Spot here on the island, and while I was waiting for my new job, I started working in a bank. So, I had a radical change from a waiter at White Spot to working in a big bank.

AH: But uh, how did the disease affect you in your personal life, or in your professional life, in any way?

DP: Well, I had to work. I don't think my partner was well enough to work at the time, I had to work to support us and stuff like that. Sorry, what was the question again?

AH: You just mentioned that your partner was feeling unwell. Was that because of the HIV?

DP: Partly.

AH: I was asking how did your relationships—professional, personal?

DP: I was new to Victoria, I didn't know anyone other than my partner, and I got, you know, busy at my job and banking. I worked at all the branches. I was out meeting new people all the time. Of course, everything about HIV was a secret in those days.

AH: So, you kept it a secret?

DP: Yep, I did.

AH: Any other changes in your life when you discovered you were positive?

DP: Yes, I got in touch with my inner shaman, and I got interested in mind-body-spirit connections. I saw all my friends getting sick and the AZT wasn't helping them and I refused to go on it, and I meditated, I went out in nature. I did what I felt I needed to do.

AH: And did you feel that helped?

DP: Yes, yes. I survived from '88 until '96 when the medications were available.

AH: I've heard in several interviews that people think that the AZT might have contributed to the deaths of people.

DP: Yes. I've heard that too. Yeah.

AH: I thought that was one that I hadn't heard before.

CA: During that period in time that you were exploring the things, the alternate things, did you join any groups or any associations?

DP: Yes, I joined a men's group, a Jungian-based psychology men's group. And I went to holistic healers, and uhm, I can't even remember the name of it—it was very, very expensive I remember that—and I worked in the bank in the day, and I waited tables at night to afford all these alternative—anything alterative, anything healthy and good is not covered, it's very expensive.

CA: Still.

DP: Still.

CA: And were you secretive with your status in all of those areas as well?

DP: Not in my men's group, no, not at the holistic healers and what not, no. At my workplace, yes. Uh, I wasn't really in the closet about having HIV, I didn't talk about it at work. And then… then after hearing a lot of negative things and what not, my—I was kind of closeted for about a twenty-year period. Yeah. My partner, my current partner, my husband and I, he opened a restaurant downtown Victoria, a successful, high-end restaurant. And we worked there, and he was like, you know, it's best that we not tell people. Because apparently there was a restaurant here in Victoria and the partners were open about their status, and it shut down.

AH: Because of public perceptions about how you can transmit the disease, that kind of thing?

DP: Mhm.

AH: So, on that topic, how did the public react, not just to you, but in general, to the epidemic in your recollection?

DP: From what I recall, everybody was afraid.

AH: But was there an intensification of discrimination, or stigma, or of homophobia?

DP: Well, yes, definitely homophobia, and I feel like in the bank that I worked that I didn't advance very much because I was a gay man. I wasn't invited out for beers after work and to go to the games, and stuff like that. I didn't really advance much. But I had my other job, and between the two jobs, I survived. The bank was good because it had a great extended health benefit plan, and the other one paid the bills.

AH: So, shifting gears a little bit—this question's in the wrong place, I'll just go ahead here—how did—what was, in your perception, the governmental response at that time?

DP: Nothing.

AH: Short and sweet. Nothing at all from government or…?

DP: I learned about AIDS Vancouver Island when I moved here and that was a support for me. There was another group called PWA, but I was kind of on the fringe of that, I didn't really get involved in that group.

AH: And how was your friend doing at this time? Was he getting better, getting worse?

DP: My partner.

AH: Your partner, sorry.

DP: He uh—he uh—he got worse and he passed away before the good drugs came out. Just before.

AH: Did you have any involvement with VARCS with your partner?

DP: Uhm, which one is that again?

AH: Victoria AIDS Respite Care Society.

DP: No. But we broke up, and his—him and his partner, they got involved with that, and he actually passed away in hospice. In half an hour I believe, getting there.

AH: What about the medical community? How did they respond at the time?

DP: Some doctors were like, woof, you know? Rubber gloves and freaked out, yes, yes, yes. Dentists yes, the glasses and the whole bit.

CA: Was there are a difference—so you were diagnosed in Vancouver and then came to Victoria. What was the difference between the medical community there and here?

DP: I didn't have much to do with the medical community there. I got my diagnosis, and my doctor at the time, he was a gay man, and most of his clientele were gay. And he lost like four hundred patients in that year, and he burned out. And we came to the island.

AH: Astonishing numbers, yeah.

CA: So, you had different experiences with the medical community, or…?

DP: One thing that was interesting was because I was from Vancouver, my first testing was done there, and I don't recall if they weren't testing at all on the island in the beginning, but I was going to Vancouver routinely for my bloodwork. And then when they started doing it here, the numbers were all out of whack. So, I continued to go to Vancouver every three months for years, probably twenty years, until I trusted what was going on here in Victoria.

AH: What do you mean by 'all out of whack' with the numbers?

DP: Uh my—

AH: Your own personal numbers?

DP: Yeah, my own personal numbers were you know, different when they tested in Vancouver than when they tested here.

AH: So you didn't trust—

DP: No, I trusted what was happening in Vancouver, at St. Paul's.

AH: St. Paul's was ahead of other people. So how did—did you become more involved with the gay community here, at that time?

DP: Well, one of the jobs that I worked at—I worked at a bank in the day, and restaurants in the evening—and most of the waiters in the restaurant I worked with were gay and we would go to clubs after work and have a drink, things like that. And that's how I met people. We were more interested in having dinner parties in each other's homes, we occasionally went to the clubs, but we weren't big club people.

AH: But how did the gay community respond to the epidemic at that time? What did you see, things happening within the community?

DP: Uhm, I would say things got quieter. You know, businesses that were really busy got less busy. It's just, where people hung out, it just got thinner and quieter, if that makes sense?

AH: Yeah, it does.

CA: Did the community kind of go underground?

DP: I think so.

AH: So, the club scene, you weren't very much a part of that, but the club scene must've quieted down quite a bit?

DP: And then we still had a strong connection with Vancouver because we were still going to St. Paul's and what not, and then you know, you could see the West End getting less populated and all the gay bars were closing down. There were so many back in the '80s, and then they just one by one by one closed down.

AH: But did people's behaviour change? I mean you, the whole gay scene where everybody's doing everybody—so the rumor goes—did that change, or did people resist that and just keep on keeping on?

DP: Uhm, I was usually partnered.

AH: So, you weren't involved in that kind of scene at all.

DP: A bit, but not so much, no.

AH: When you did—did you come out to your family?

DP: Yes, I did.

AH: Early on?

DP: I was about eighteen, nineteen, and I came out to my sister and then she went home and told my mother.

CA: [Laughter] What are sisters for!

DP: I know.

AH: So, when you got your diagnosis, did you come out to your family with that?

DP: My sister again [laughs] was with me in Vancouver and she was there, and she went home to Ontario and told my mother. And I got a very negative response when I went home for Christmas that year.

AH: Oh my. Have they—did they become educated and come around?

DP: No. My mother is the queen of denial. She's uh – she moved to Victoria, and in that twenty year period she was here, we were very, very closeted again. About having HIV and whatnot. I have my birth family, and then I have my family that my buddy, she's been my buddy for twenty-five years. And her children are like my siblings. I have like two families.

AH: Oh, it's nice to have that.

DP: It's wonderful.

CA: So, your family of origin that caused you to go back in the closet?

DP: Yeah, it was shameful for them that I had HIV.

AH: And how did that play out? They just cut you off, or what happened?

DP: Initially, yes. I went home my… my best friend… I was working for White Spot and there was a union strike and I was unemployed for six months, living at a friend's, not have a lot of money, got my diagnosis, my partner and I were separated at the time, and uh, we um… Sorry, lost it.

CA: Strike, partner separated?

DP: Right, um, strike, partner separated…

AH: We were talking about the response to your coming out with the disease.

DP: Right. Well, my best friend in Ontario, who's still my best friend, we've been friends since we were like eight or ten years old. She lives here in Victoria now too. She bought me a plane ticket to go home to Ontario and she thought it would be best that we go see my family and that her and her husband's little children come with, and kind of be a buffer. But my mother's reaction was you know, it's Christmas. "Your sister tells me you have AIDS and it's Christmas, and let's not talk about it and your step-father's here and your uncle's here and your aunt's here." And so, it was like, it was horrible. I was in such pain, in such grief and wanted to go home for support, and got nothing. And then after that, I came back to BC and I got a phone call that I had given HIV to my little sister, my mother thought through food or through something like that. She had something like hepatitis and that was my mother's only focus was her youngest child. But that's the way it's been since she was born. It's true.

AH: Oh, those little sisters.

DP: Half-sisters. Yeah. I always called her my sister but she refers to me as her half-brother now, and she's cut me out of her life totally. And that's because of that, she was seventeen at the time, certainly old enough to understand what was going on, but my mother sheltered her, and wouldn't tell her, and secretly had her tested. And you know, she would call me all upset about that. And it was like, okay? You know, no support from me at all. And she didn't come around for years. I was here dealing with all this stuff, I was starting to get KS. I got diagnosed in '88, and the middle of '89, I was told I wouldn't live to my thirtieth birthday.

AH: Yeah.

DP: And that was thirty years ago. Going on thirty-one. [Laughter]

CA: Look pretty healthy.

DP: I'm very healthy, yes. I've healed so well with my knee surgery. I'm non-detectable, of course, and after my T-cell count, my helper T-cell count was one-thousand-four-hundred before my surgery, and yeah, that's just quite high. And I thought, oh, I had a dentist appointment the other day and I thought, I wonder if that's come down from that traumatic surgery. And I called my infectious disease doctor and he said, "Your numbers are now two-thousand." I found that the other day. So, I'm all psyched to get my other knee done now.

CA: All systems are go.

DP: And I think it's a riot that I—you know, I thought I would live to be thirty and then the next thought was that my father died around thirty-six, I thought I would die at that age. And now it's like, I'm living in fifty-five plus housing and I'm getting my knees done. I think it's great. You know, do all the stuff—

AH: Do all that stuff that old crocks do?

DP: --that almost sixty-year olds do. Yeah, exactly. I'm still here doing it.

AH: So, you had the—did your family get educated at all, about the disease?

DP: I would say somewhat. My sister was more proactive, I would say. And not – I would say not so much, no.

AH: So, did you turn to the gay community for support at that point, or how did that work?

DP: Uhm… I'm trying to think of the timeline. I met my partner, John, around 1990 and we've been together since then, and I felt that he loved me when nobody else did. And we're going on thirty years, uhm… medication—anaesthesia. Yeah, he's a great guy, great support. And then I got involved in AVI and I met Nancy Bansgrove, my buddy. That was twenty-five years ago, and that family took me in and embraced me and the children, and then the grandchildren came. And I'm like part of the family, I'm an uncle, and it's great.

AH: Ah, that works. Yeah. Were you involved in any aspects of AIDS activism, act-out kind of stuff that's gone on?

DP: Well, I've read about it and I saw it on television, and of course I had to act-up myself quite a few time to get what I needed, you know, with the medical community and…

AH: Pounding on desks?

DP: Hmm?

AH: Pounding on desks.

DP: Mhm.

AH: But sort of the public manifestations of that kind of stuff, were you involved in any of that?

DP: Yes, but more so when I was in the States, not in Canada. I went to a—it was called Lava Rock, it was a community with people that had terminal illnesses, people with cancer, AIDS, all kinds of illnesses were there. And I would travel down to Portland and be in that community, and act up more when I was in the States than I would in Canada.

AH: It felt a little freer?

DP: Yeah, I guess, I don't know. I mean, Victoria's a small city, or it was back then – it's getting big again, I'm thinking about moving up-island somewhere. Traffic, and, that's why I left Vancouver.

AH: Yeah, we barely got here. So, how did the community—the gay community, whatever, define that—deal with the burden of care and support, you know helping out others as they were getting sick.

DP: Mhm. There were – there were supports, and at one point in my life, I believe it was PWA I had some support from there, like volunteers would come to my home and help me with things, and help clean the bathroom. Back in the day, there were VON nurses that would come and help you organize your medications, and all that kind of stuff.

AH: So, how sick did you get?

DP: Well, I almost died in my late-twenties. I was, you know, getting opportunistic things and uh, lesions—but I was also on my spiritual journey—mind body spirit—I was working on healing myself, and meditating and visualizing it going away and all that kind of stuff, and somehow I got through it.

AH: And then the good drugs came along.

DP: They eventually came along, yes. I went on some not so good drugs and some horrible experiences. Horrible, horrible side-effects.

AH: What were those?

DP: Uh, one of them I recall was DDI. It was a big one that came after AZT. But anyway, whatever.

AH: A few false starts of dealing with this stuff. But how did people deal with the grief of so many people around them dying?

DP: [Sigh] It was very difficult. And even to this day, when I go to Vancouver, I see a lot of ghosts [sobbing]. I don't want to talk about that.

AH: Fair enough. So, I'll move on. How has the epidemic changed your community, or communities as you define them? So, did it damage the community, or make it stronger, over time? Obviously, it did the damage of loss, but over time?

DP: I kind of lived on the fringe of the gay society, I have to say. Like, I was in mainstream banking, and then my partner had a mainstream restaurant where we were quiet about it, and when we needed support it was there. And just recently, I needed support from AVI and I got it. And I waited a tremendously long time for my knee surgery, and I really felt that I was being treated differently because I was HIV positive. And my doctor—I went down there with the Executive Director of AVI as a support person, and then he changed his tune and then I got a surgery date the next day. After a good three plus year long wait.

AH: So, you—you felt that you were being discriminated against?

DP: Absolutely. Just—just months ago. Absolutely.

AH: Interesting. Well, how did that play out? You just kept getting bumped down the list or…?

DP: Yes, I kept getting bumped. My surgery was on, it was off. They kept repeating the test—the blood test—the EKGS—it was a horrible period, and I gained a lot of weight, I was housebound, I got very depressed. And I was—the year before my surgery was a year of hell.

AH: Well, that's… So, back to that, how did you—how did you come to perceive that it was discrimination?

DP: Pffft, I don't know, I'm fifty-nine years old and it got that vibe. And I didn't know if it was homophobia or HIV-phobia that I was, you know, that vibe that I was getting. And I felt that I had to jump through hoops that people didn't have to, to get their surgeries, and at one point I told my RN that I felt like I was being discriminated against, and she just assured me that I wasn't. And yet my surgery got, you know, postponed again. Until, like I said, the Director of AVI went to one appointment with me, and I called and said I want to go on a wait-list, and I got a phone call the next morning, and I had my surgery three and half weeks later. I'm not at the three-month part. I'm still recovering from it.

AH: Who was that, Katrina who went with you or?

DP: Uh, Kori.

AH: Kori. Ah. Um, any change in your perspective about HIV over time? The introduction of new drugs…

DP: Well, it was terrifying in the beginning, of course. It got more hopeful as the drugs got better. When we were first on antiviral medication, before they had the uh—the other ones, feeling more hopeful. And then, I think it was '96 when they got the good antiviral medication, and it just turned my life around.

AH: Did you have anything to do with Positively Fit?

DP: Yes, I did. Yes, I used to get a Y-pass, and do that, yep, mhm.

AH: Right. Did you get anything out of that?

DP: Yes, I did, mhm. Exercise and uh, met—hung out with some gay men I knew from the community and you know we would go out for lunch and things like that.

AH: So, it had both social and physical effects for you.

DP: Yep.

AH: Yeah. Here I come to the end of the list. Anything you can think of that you would—if you were in a position to do so—advice for health professionals?

DP: Advice for health professionals. Wow, I didn't expect that.

AH: I mean, expect that something like this—diseases evolve, something's gonna come along—whether it's gonna affect one community, like the gay community, or not, whatever, what would you suggest to the medical community? They're pretty slow on the uptake, or government certainly was, and some of the medical community.

DP: Chill out, take a deep breath, and get some education.

AH: There you go—the quotable quote from the interview. Any advice for future generations? I mean, at this point understand that the incidence of AIDS or HIV is going up, because people think, oh well, we don't have to worry about this.

DP: I don't know a lot about that. Like, in my life, the last, you know, fifteen, twenty years being HIV positive is just a little part of me, I don't identify—it's not my identity it's just a small part of me. I hear about new drugs like PrEP and I've heard some negative things about them and that frightens me. And that young people think that they can have unprotected sex and that frightens me. I think that, you know, no matter what, you should always use a condom.

AH: Alright. And is there anything else that you'd want to say at all, that you want to say to whoever might be listening to this?

DP: Um, I wanna say that the best thing that came out of this for me was meeting my buddy Nancy at AVI, and having that family and the siblings and the grandchildren and being a part of that family. When my husband and I got married fifteen years ago, Nancy and her husband, they were our witnesses at our wedding. They've been a big part of my life. And now they're aging and the roles are kind of reversing. And it's great, they're a great family. I love them.

AH: Uh, okay, anything else that you want to uh throw in there?

CA: Actually, there is. So… actually I need a minute.

DP: I have those moments too.

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DP: --participating uhm, uh… Kori told me about it and the AVI community's always been there for me, and Nancy had two buddies before me and they're not even aware that we still have a relationship twenty-five years later. So, it was for AVI I guess.