“HIV in My Day” – Victoria Interview 7

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Interviewee: Anonymous (P); Interviewer: Art Holbrook (AH); Also present: Charlene Anderson

Art Holbrook: I’m sorry—

Participant: Start again?

AH: --there’s one button I didn’t push.

P: So, we’ll start again?

AH: Yes, please. I’m sorry.

P: That’s okay.

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

P: Back in the—probably the 1980s, there were just little glimpses of this disease on the television. And the glimpses were full of fear. There was something that was showing up and they didn’t know what it was, and then the only thing that they would tell us was if person X had sex with person Y, person X and Y would pass the virus on to all of their multiple sex partners and it would just explode through the population. And that was – it was interesting to me because I realized afterwards that that wasn’t true, and what probably was exploding was the virus in our bodies from the time we were infected. It was just taking over our bodies. But they didn’t even understand that in the early days. The only thing that they really wanted to know was how to isolate these people who were potentially spreading this virus. So, there was lots of stigma, there was lots of fear, there was lots of reasons not to tell anybody, which I did a pretty good job of for a very long time. It took me years and years before I told my family. I had one friend who I confided in, but I lived in a situation in Vancouver where I had a lovely house I was staying in. The father of a friend of mine from Victoria—really kind man, but not one who I thought would understand anything about HIV. And I didn’t know very much about it, so I wasn’t able to give people information to calm them down. So that was a difficult time, very difficult.

And the only, the only little niggle of positivity in that was a support group that I went to, and that was in the West End of Vancouver, and they met I think once a week – it might’ve been less frequently than that, but at least once a month. And I would go and I would meet with these gay guys who were at first very shocked to have a woman come into the room. “How did she get it?” You know, there was just lots of curiosity and – but unspoken words in that room. And there was so much grief. I just remember people crying at every meeting, there were boxes of Kleenex everywhere. Somebody would come one week and they wouldn’t come the next week ‘cause they’d died in the meantime. And it was just sudden and unexpected, and just lots and lots and lots of illness. And nothing, there was nothing that doctors could do. So, we were just there to support each other in whatever way we could. The fellow who I met when I first went to that support group, met me outside so that he'd walk in with me, so I wouldn't be so uncomfortable walking into the room. He's still a really good friend to this day, and probably because of his actions at that time. There were a couple of guys who were running that group – one of them died shortly afterwards and that was just the order of what was going on at that time. It was really, really, really sad.

And there was finally a woman who came into the group. Her name was [name]. And I remember being overjoyed to have another woman in that support group. And I walked over to her and gave her a hug and… and she lived maybe a couple of months and then she died. She was very public about her infection, and she did newspapers stories and all kinds of stuff that was really good for getting the story out there, that there were other people that were being infected other than gay men. At the time, it was mostly gay men that knew they were positive. They wouldn't test women, until they were really, really sick. In that instance, I was really lucky—I was infected in Africa—I came back from Africa having spent six months there. I was doing research for a master's degree, I'd been still water which I knew had bilharzia in it, I'd eaten really strange things like goat intestine, I was sure I had amoeba already running through my system. I wanted to be tested for everything. I had no idea that the test would come back HIV positive. I don't even remember asking for the test in fact. But my doctor couldn't tell me face-to-face, I guess, but he didn't work very hard at it. He just phoned me at the university common room, at the university—Simon Fraser University. I was sitting there working on a paper with some other people, and the phone rang, it was for me. And he just said, "You're HIV positive. You need to see a doctor right away."

And I was just shocked. Shell shocked. And I actually remember walking out of there. And I was supposed to be on a field trip that afternoon, and I just went over to the guy that was the department head and I said, "I'm not going to be able to go on the field trip this afternoon, I don't feel well." And he said to me, "You look like death." And it was just the worst thing he could have said—but he had no idea—I mean I was just so white, and so scared. I remember going home on the bus and just wondering if people knew I was HIV-positive, and what did it mean. I went home and went up the stairs to the bedroom I was staying in, and I really thought I was going to die that night. That's how little information there was around in those early days. But it's a lot different now, it's really, really different now. And it got a lot different, even then. When I didn't right away, I knew that I could do a few things, and I loved running, I loved playing soccer, so I played soccer for as long as I could. I finished my master's degree, I went back to Africa, did some more research there. The medical community didn't really support me, my academic community didn't support me, because they didn't know what was going on. And my friends were just friends, and uh, a lot of them, I didn't tell. I just told one friend and that was it for years. I was so afraid that people would treat me differently, that they would not like me, they would not include me in things, they would judge me for sure. And I just wasn't ready for that. I didn't want that to happen. So I—I hid it for at least four years, I think.

And then—well, no, I didn't, 'cause I did tell someone else. I met a guy on the ferry, travelling to Salt Spring Island where I was staying off and on. And I met this guy, we were chatting and stuff, and we got talking about things and eventually we found out that we had lots of things that we did in common, including diving. So, I had to – I had some friends who had crab pots and we had to go diving on these crab pots one day. So, we got together and we went diving, and then we had dinner together and eventually, he leaned over to kiss me one night. And I just went, "Uh, I have to tell you something." And I told him that I was HIV-positive, that I had the AIDS virus in my body, in my blood. And he just looked at me and he said, "Well, I guess I've got two choices: I could leave you now, and never get to know you or we could we have as long as you have to live together." And we did, we had a number of years together, until he died suddenly at work. And so, he stayed HIV-negative, stayed healthy in that way. But accidents happen, and he died at work. And that was a huge lesson to me, that this virus might not kill me. It might be a bus, it might be a plane crash, it could be anything. And the virus didn't need to have that much power, and I needed to let that go. But it really took a strong-willed man to introduce that to me, because I wasn't open about being positive to people. I remember eventually telling another friend, and she said, "Oh! We should take a holiday in Hawaii then." 'Cause that was her solution to everything: if you're going to die, we should have a holiday in Hawaii. So, that's what we did. And yeah, I did a lot of things in the early days without really a lot of people knowing what was going on. I wanted to talk a little bit about the medical community, in the early days—I think we missed that part.

AH: Go right ahead, go right ahead.

P: Okay. Yeah, my first experience with a doctor who knew about HIV was a doctor who's very famous right now, Julio Montaner. He was probably one of the only people in Vancouver in the '80s that was working on HIV, but he wasn't very patient-friendly. And so, he just showed me a graph, a bell curve, "and here's where you are likely right now, and you might have seven or eight years, and then you're gonna be here, which is death." And really that was not a very optimistic approach to living with HIV. And we didn't actually – I don't think we called it living with HIV in the early days, I think you had the AIDS virus was really what it was. I came to see another doctor in Victoria, because Victoria was my home. I was going to university in Vancouver and living there while I was going to university, but I am not a big city girl. So, Vancouver was just too big, and I moved back here and saw a doctor—Doctor [name] here—and I remember Doctor [name] pulling a book out—a picture book—of the worst cases of thrush and Kaposi sarcoma and all kinds of things like, I didn't need to see this. It was really not good. But they had no idea what would happen. And the only thing they really thought was that they needed to watch me for pneumonia. That was one thing that they wanted to check my lungs every time, to make sure I didn't have pneumonia. Yep, that was…

AH: So, how did you actually get to learn about the disease? The doctors didn't know and—

P: The doctors didn't know anything. I think actually it was here at PWA that I learned a lot about the disease and I – there was a fellow who's still alive today, [name], who was doing a lot of research in the early days. And he would pull out papers and he would read about what was going and we, we really kept up on the research in the early days. We wanted to know everything that was going on. I remember the support group in Vancouver, there was a hum about this drug AZT that was coming out. And people were wanting to try it. And then I was watching people use it and get sick and die. And I didn't see anybody recover, who was using AZT. I didn't want anything to do with it. I didn't want to take any drugs, I'm not a person who likes medicating myself at all. Headache? Just wait it out, it'll go away, that kind of attitude. And so, taking drugs was pretty foreign to me.

I eventually met this fellow I was telling you about, and moved to Salt Spring Island, from Victoria. And on the island, there was a doctor that I had who was a woman doctor, and I thought that would be great to have a woman doctor. But she was horrible, she thought that she was doctor god too, and I started getting sick after a while. I had a really high-pressure job. I graduated—first woman in my class to graduate—second person to finish my master's. I just wanted to finish things, I had this sort of urgency to get that done. And got a job with the provincial government here in Victoria, working on policy around environmental industries, global environmentalism. And then, I love indigenous peoples, and so I got a job working on the Nisga'a land claim ultimately. And I was flying up to Terrace and back and over to Vancouver for meetings. It was really busy and really hectic and a lot of stress. I would try and meet with Fish & Wildlife guys. I was working for the Ministry of Environment on their Aboriginal portfolio, and these guys were "That's our land. Why do they think that's their land? That's crazy. There's no way that they're getting any, any of the Crown land. That's where we go hunting and fishing." And it was just an old boys network that they weren't giving anything up. So, those were the people that I had to work with. And I was very sympathetic to the Nisga'a and their determination to have control over the lands that they had traditionally used. And especially the fish, the fish were really, really important there. And I'm sure they are in every treaty, but ironically the federal government wouldn't talk about fish, because they had to make deals with the U.S. before they could make deals with the Indigenous people. So, there was all kinds of stress.

And I started going downhill really quickly. My doctor said, "You have to start taking AZT." I went, "I'm not taking it." And she said, "No, you have to take it. It's the only thing that we have that will help you." And I said, "No, I have a choice, and I'm not taking it. I've seen too many people get sick and die with that." And she said, "If you want to do that to yourself, you just go right ahead." She just had no respect for that, and I knew I needed a new doctor at that point. And I went back to Vancouver, because by that time—we're getting into the late '80s, early '90s—by that time there was a little more knowledge going on with that. And I heard that somebody at BC's Women's was working with women who were HIV-positive. So, I went and this doctor interviewed me for three hours, not about HIV – how did you get infected – none of those kinds of questions, but what's your family history for heart disease, what's your family history for arthritis, what's your family like? Do you get along well with your family members? All kinds of questions that were so important to my health and to me as a person. And so that was a huge change. And I decided right on the spot that he would be my doctor. And eventually his little group of people became the Oak Tree Clinic. And that's where I go to, till this day. I will take the ferry over to Vancouver and go there, because the care for women is so good, and so comprehensive. It's not about what's going on in this vessel, it's about how am I feeling, and when my partner died suddenly at work, it was all about how are you coping? Are you doing okay? Do you need this, do you need that? And anything I would have—I remember thinking I was having a heart attack 'cause I had such pain in my chest. And it was grief, but I had no idea what grief felt like in my body. And so, he would check for everything, I would do all the tests for heart attacks. And anyway, very lucky to get that kind of care, and also the Positive Women's Network, really instrumental in the first years of my care.

Now, I'm gonna go back, because somewhere in there I was getting information from [name] at PWA, and somebody asked me if I'd join the board, and I said, sure, I would join the board. And so, I sat on the board for PWA, but there was fellow I remember, he was going to be the treasurer, and that was the only other position that we needed on the board. And I think I was the secretary. And the treasurer was in the hospital for some routine stuff. He never left the hospital. He died. Within a week he was dead. And that was what was going on. And within I guess, oh, three months of me joining the board, I was so sick that I was doing the board meetings from my bed at home. So, there was just this thing that would happen where all of a sudden you just would get so, so sick with something that seemed like it was like a really bad flu. Or it might've been pneumonia. But you just couldn't lift your body off the bed or the couch. And you just would drag yourself around to do things. And the things that you would do would be to watch inspirational videos, read books that would inspire you to stay alive, look for clues for what people were doing in San Francisco area to deal with HIV. And so, we were brushing DNCB [dinitrochlorobenzene] on our skin to try and give ourselves an immune response that would heighten our immune system. We were doing tai chi or qi gong, anything to try and keep our bodies in a balanced state. And I was really lucky, I had a really good naturopath who recommended I go see a woman who did therapeutic touch, and I started receiving therapeutic touch on the island—Salt Spring Island—and then was told to go to Orca's Island, where the person who founded therapeutic touch, who was a psychic healer could give me treatments, which were really helpful. So, every summer I would go to Orca's Island. And when [name] was alive, he would fly me in his magic carpet—he had a private airplane—so we would leave from Salt Spring Island and fly over to Friday Harbour, and clear customs and be on Orca's Island within twenty-five minutes. Now, I take the ferry. I still go to Orca's Island every summer. But I take the ferry, and the ferry and the ferry, and you finally get there, but it's not like flying over there.

So, I was lucky, lucky, lucky, on one hand with this wonderful man in my life and the opportunities that I had because of my education, and on the other hand, I was unlucky with the time that I was diagnosed. I was diagnosed so early, infected so early with the virus, and probably didn't have much of a chance to live. A lot of the friends that I had got really, really sick and several of them died. We had a support group that we formed on Salt Spring Island and there were two women, and one man—the most unusual support group for HIV anywhere. There was [women's name], and myself, and a fellow named [name]. And we had this support group and we would just tell each other what we'd discovered, or if one of us was really, really sick and the others could manage, we'd make soup and take it over to the person who was really sick. And like that, we just kept each other afloat. And each of those guys got so sick a couple of times, that I was sure I was gonna lose them. And that would be really, really, really terrible, because by that point we had become so close and so connected around the HIV. And other things, we—we would—when we were strong, we would go for hikes and we would eat together, and stuff like that. Anyway, they're still alive, all three of us are still alive, and the support group now has fourteen people. Mostly men now, but there's still quite a few women on Salt Spring who live with HIV who are part of that support group. And yeah…

AH: What was the mainstream response? What did you perceive as the mainstream response, the rest of the world?

P: The rest of the world was cruel. The early candlelight vigils made me realize that I was now part of a community that was unwelcome in the city. People would spit on us, people would shout names at us when we walk down the streets. We would have a march and in September, and there would be people that would support us, but there would be a lot of people that would be extremely rude and unsupportive. And I remember it was huge when—I think it was Dosanjh, was the first, was he premier?—anyway the first political leader who was willing to be amongst the gay community and ride in the gay pride parade, and stuff like that. I became very active in the gay community, which I had never been before. But I feel like that's one of the blessings of HIV, is that you get to meet all these wonderful, wonderful people. And a lot of them are gay men. And they were what kept me alive for a long time. There was another source of information in the early days, and that was CATIE [Canadian AIDS Treatment Information Exchange], and that's still an active source of Canadian information. But we would get fact sheets from CATIE, and the three of us in our support group would share them. There were so few people in the mainstream that I would tell that I didn't know what the mainstream response would be. And it was probably not until much later, after [name] died, I re-partnered with a fellow and we started doing work in Africa, and then I started being much more out about my status, and just saying, you know, we're so lucky here in Canada, we have medicine. In Africa they don't have anything to deal with it, and it's a horrible thing, to not have medicine.

So, when the medication first became available in Canada, I was aggressive about getting it. And really lucky in that I knew my family would support me if I needed it but I also—financially—I also knew that my doctor in Vancouver would work with a doctor in the States and we could get a prescription and get the drugs to Canada, before they were available here. So, I got Crixivan before it was even an experimental drug in Canada. I paid for it and had it sent up here, and lived on the regime that you have to live on in the early days of that. I haven't told you about the mainstream response but let me continue with Crixivan, because I had to take forty-nine anti-retroviral medications every day. And some of them were with food, and some of them were without food, and you had to set an alarm clock. One of the drug companies made actually an eight-alarm alarm clock which I still have, so that you could set an alarm for eight times a day and take these meds as you needed to. Some of them—one of them—uh, DNCB about that big, had to be dissolved in water. And if you didn't have any water, you could chew it, but I found out later that it sort of dissolves your teeth if you chew it. There was something in it that would make your teeth rot right at the gum line, and so I had a lot of cavities from taking those pills. I had gum disease, which was a side effect of the HIV medicine. But I never had a problem with dentists, that was one thing that a lot of people in the community had a hard time finding a dentist. And I remember telling my dentist I was HIV-positive, and she just said, "Oh, I guess I'll just take universal precautions, like I should anyway." She was a very, very bright woman, and had a few people in her practice who were HIV-positive. And if people couldn't pay for a dental appointment, she got another piece of artwork on her wall, or something like that. She was just a very wonderful, wonderful woman. She retired, and I now have her daughter as my dentist. So, that's great.

Um, the mainstream community, I was mostly worried about my family. I knew at some point I needed to tell them. When I started getting sick, I had to quit my job. I just wasn't doing anything, and I used to travel back east to visit them. I couldn't do that anymore, it was too much work. And so, I invited them to come for Christmas so I could tell them. And my dad's—my dad was, my dad died a year ago—but my dad was a veterinarian, scientist, a research scientist. And so, I got all the research I could get and put it in a big stack for him – I knew that was the best thing to do for him. My sister was an accountant and I knew she would be the one to figure out how much money I needed to live, for however long I was going to live. Just telling my family was really hard, but the reaction I got was not the reaction I expected. They—I was totally embraced and loved and supported once I told them. But I feared so much, you know, my expectations were so tinted by what I'd seen on the streets in Vancouver. Eventually, I got to the point I where I could talk openly being positive, and then, I haven't gotten a bad response from anybody from doing a public talk about being HIV-positive or anything like that. I recently had a bad response from somebody because of public art, but that was a different situation.

AH: What was that?

P: It was Dream Colloquium in Vancouver. The president of SFU decided that HIV would be the subject for his Dream Colloquium for a semester. So, we took over a bunch of art and put it up in a big room at their downtown campus—oh, I can't remember what the name of the room is—but huge room. And we had the *We Are Here* photographs, we had a beautiful collage that was done by Kath and Marguerite that had all of those pills I was talking about, and plus some syringes, and IV bags, and all the paraphernalia that was associated with the early days of living with HIV. And there were some photographs that were taken by people, I think in Vancouver, who were suicidal around HIV. That's another tricky, tricky issue is the mental health issue. But… and then we had—oh the body maps, of course!—we had the body maps of positive women were there. So, I helped set up the gallery, and I was there during the day when people walked in, and one fellow walked in, and he just said, "We don't do this to medicine. Medicine is sacrosanct. My father is a very famous doctor in Israel and research is what you do with medicine. You don't make art like this about it." And I said, "Well, you should look at some of this art." And I tried to talk to him, which was stupid. I should've just said, "You're in the wrong room, there's the door." But anyway, it was a very difficult time and he eventually said, something like, "People who are HIV pos—people who have AIDS are cursed, and they deserve to be cursed." And that was his attitude. And so that was very hurtful, even now that kind of stuff has a way of getting in under my skin and really, really hurting. And so, yeah, I try not to put myself in those environments, but I think I have better tools now for dealing with somebody like that. Show 'em the door.

AH: So, you mentioned becoming active in the HIV community. You were with PWA—

P: PWA, and then later on, the African situation was my big thing. I was trying to do someth—I wanted to give back actually. So, I went over to Oak Tree and I asked if I could do something, and I love to write, so I said, could I write something up for families that are dealing with a child with HIV so they'd have all the information that they could possibly have? And my HIV doctor dealt with adults and he thought it was a great idea. And I put together a proposal and stuff, and they had a bit of a problem in that I would need to look at files maybe to find out who to give this information to, but we were kind of working on it, and then his partner who worked with children said, "We hardly have any kids anymore who are HIV-positive because we're treating women now. We're treating the women with Nevirapine and other drugs, and they're not having positive kids anymore." And so, it was like this happy story, but kind of sad because I thought that's what I might do to give back, or help with research. I ended up starting an NGO that does work in Africa called Positively Africa and we would connect with African community groups. And I finally got the courage up to go back to Africa, see what had happened to the country that I knew, which was Zimbabwe, which was not only affected by HIV, but also really bad politics.

And I—we went to Rwanda because we'd been involved in a project to bring water and electricity to a group of women whose lives had been altered not just by HIV but by a genocide that happened in their country, so they'd been raped and tortured during the genocide. And so, a community had gotten together called the Rwanda Women's Network – they'd build houses for these women, but there was no water and electricity. So, the first project that I had—and it wasn't really the first project, I just thought of something else—that I had to do with Africa this time was to get money for the water and electricity for this village. So, my partner and I did a lot of fundraising at the time, and I did a lot of speaking about HIV and Rwanda, and we raised thirty-five-thousand dollars for the water and electricity. And once they had their water and electricity, we went over to see what difference it made to that community, and thought, wow, that's huge. Because they now could have a clinic, they could have a training centre, they could sell water to other contractors who were building near their village. And it was just unbelievable what mushroomed out of this water and electricity. It wasn't twenty women at the Village of Hope, it was two hundred, because it became a big centre for people. And I'm still in touch with people at the Village of Hope, but we found that there were other projects where people just needed a little seed money. There was a feeding programme for orphans to get lunch, and that project was feeding people once a week, and that didn't seem like enough to us. And so, we got money so they could feed people three times a week, which still isn't enough, but that was all we could manage on that one. And then there were other grandmothers that needed money to use the products that they could grow in this really sandy soil, which was peanuts, ground nuts. And so, we bought them a peanut roaster and grinder. And we did all kinds of fundraising for healthcare, for childcare, around HIV, always communities of people living with HIV in Africa.

And I did that for ten years, and it exhausted me, just like working with the other projects, so I had to pull away from that to—I had to pull away from that really because I ended up with PTSD. The last time I went to Africa was after a relationship break-up with a partner who was angry, probably angry about getting old, which, why bother, you're going to get old whether you get angry about it or not. But anyway, his anger manifested in a way that wasn't safe for me anymore. And so that relationship blew up, and I wanted to go back to Africa to monitor what was going on with the projects we were funding, so I went back. But watching what was happening to women in certain situations where they would be put in a building way far away from everyone else, and just isolated, because they lived with HIV. Even though communities had HIV riddled through them all over the place, there was still this stigma that was so strong, and especially targeted at women. And women who were widows were treated worse than women who weren't widows, and it was just too much for me. And I couldn't do enough, and I couldn't do something for everyone, and even what I was doing would last for one medical treatment, or one year. And that wasn't enough. So, when a person gets into that situation, and there's this repeated anxiety, and it just gets to be crazy. And I was forgetting to take my pills, and I was not acting in a way that was healthy for myself. So, I slowed down the work with Positively Africa, and we're about to let it fold, because there aren't enough volunteers to do that work. Which is really sad, 'cause there is still a ton of work to do in Africa, where it's a lot like it was here in the early days of the AIDS crisis. Only the government is a lot more corrupt. There is no BC Centre for Excellence which guarantees medicine for everybody, so. Yeah.

So, that's what happened, but in the early days, even when I was really sick, I remember I used to have plant sales at the Salt Spring Market when it was a little market. And I'd get together friends and we'd grow things and we'd bring them out, and we'd have some project in Africa that we'd be raising money for, because I just felt like there was something that we could do, some little thing we could do. So, when [name] died, I remember I'd just had a plant sale at the market, and my neighbour—[name]'s neighbour, really, said, "You don't need those plants to sell. Why don't you give one to everyone who comes to the memorial service and I'll give you two-hundred-dollars for the lot of them?" And so—yeah, I know—we sent the two-hundred-dollars off to Africa, and everybody had something to put in their garden to remind them of [name]. And I had something even left to put in my garden that I had for years and years, to remind me of this fellow who was pretty important in my life.

AH: You know I went to Africa with [name] and did a show about her?

P: Ah, I remember.

AH: So, I'm relating to some of the things you're saying. We toured through Tanzania and Kenya and Uganda, looking at AIDS projects after we finished shooting the film. It's really interesting to see the differences between the countries and how they were dealing with it. Uganda was way ahead of everybody else at that point. Very sophisticated in their—

P: And you could—and then what happened was the US President convinced—wasn't that the Bush era? The US President convinced Uganda that they needed to have condom use only, that that was the most important thing? Abstinence and condom use, so a lot of the training programs just went—

AH: Yeah, that kind of crap.

P: Yeah, there was just so much horrible stuff that happened, and then didn't happen. Just give it and take it away. But you know, even in Canada, when I did the cocktail glass and took it across the country, PEI is just in the – in a dark cave when it comes to HIV stuff. There's a little tiny office somewhere next to, I can't remember what's next door, but it's just in a dingy part of Charlottetown, and there's two people trying frantically to work with all the people in PEI who are hiding because it's such a small community, you don't want anyone to know you're HIV-positive. So even in our own country there are people that are little pockets of resistance where we need to fight for resilience instead of resistance. Yeah, yeah, no, it's hard. And it never goes away, because the way that the courts are responding to criminalization of HIV is all about discrimination. And deciding who's good, and who's right, and who has a voice that you can trust. And so, there's still lots of examples where we're stigmatizing this one disease more than any other disease.

AH: Slightly different here – how did the HIV community, the positive community, deal with the burden of care and support? How did people respond?

P: Ah, that was hard. I mean, just like I'm saying, people would take it on. Like, [woman's name] would try to get support by being out there, and then she died. Like, people would take on too much in the community, and then burn out or die. That's really burning out. It's just—it is always really hard, because we're always looking for somebody to represent women or somebody to represent people living in rural communities, or somebody—and so if you step up, then you get used and used and used. It's getting better now, when I think people recognize the need for psychological support—psycho-social support. When – in the early days, we never got paid for anything we did. There was just no pay for offering yourself. I sat on a national committee—Blueprint for Action on Women and Girls—none of us got paid. And it was just months and months of putting stuff together for the AIDS Conference, finally getting more women involved in the international AIDS Conference. All of that kind of stuff was all done by volunteers. You're looking at—we're running out of time?

AH: No, I don't know what it's doing, it doesn't tell me. I'm just hoping everything's okay.

P: So, I think that the community suffers a lot. And I don't know aside from—and I've been reflecting on this quite a bit—being really, really careful to offer people social and psychological support when they're doing this work. Because there's just these edges where you're doing fine, you're doing fine, and then somebody just gets in there and they get under your skin, and you're gonna tumble. And we've got one peer support worker in Vancouver who was great, and she had been on the street, and then she got off the street and she was doing really well. And something happened and she tumbled back into use and abuse of street drugs. And so, she's totally unavailable to anybody, including herself, right now. And it's so sad, because there she is an incredible resource just wasted in the most unnecessary way. And I don't know how we can always know when to give people support. Maybe we have to get better at asking for it when we need it. But this is hard work. And there's lots of grief. Always, there's grief. Our community is closely linked with the community that's dealing with the opioid crisis right now, and there's lots of grief there. And we don't deal with it in a good way, we don't deal with dying in a positive way in North America. Even a natural death we don't deal with very well. And I think we'll finally come to a place where we'll finally get the idea that sometimes this vessel is completely used up and it's time to just let it go and let the spirit out. Let the genie out of the bottle. And celebrate that. And so instead of mourning all these deaths, if we can start celebrating the spirit of that person who's passed away ascending, in whatever way we believe they ascend. But we know that energy is not lost, we know that energy continues. So… people don't just disappear. But I don't think as a community we recognize that, and we don't deal with it. And we don't have enough support for each other, enough chance to sit together and talk and drink wine and have good meals and share stuff. We're all too busy.

AH: Did you ever have any involvement with VARCS and its respite care?

P: Yeah, I didn't – I mean, except they would be part of the meetings. Like the VARCS—in the early days AVI, VARCS and PWA were a real closely-knit trio. And then AVI started getting all the money, yeah, and just getting huge and things just blew apart. But yeah, I knew a bit about VARCS, but did they do that kind of work?

AH: Yeah, they were originally set up as Victoria AIDS Respite Care Society, and they had a series of homes where people who were, you know, in extremums would go. It was mostly partners who were caring for them and were wearing out doing it. So, they could have a few weeks off.

P: But that's end of life support, which is a little different than living life support, I think.

AH: Okay.

P: I think we need a VARCS again, but it's to support the people who are living life. Like, what we're doing right now, in the AIDS movement and in the movement to deal with homelessness and all of those things is we're burning people out. And what we need to do is get together in a place where we can rest and relax, get respite, ourselves. If you can afford to do it, people go to Mexico in the winter and they get rested, and they get energized to do it again. But not everybody can afford to do that. So yeah.

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

P: Oh, I think we're so much wiser. We're so much… there's so much heart. I think we're really aware of how much we love each other, in a way that other communities aren't. I see that in the positive women that I hang out with, and I think there's a lot of support for each other and encouragement. The competition aspect of limited resources, I guess, is one of the things that's a bit difficult, but it doesn't seem to be so strong in the communities, the people that I live with. There's such an awareness—well, for instance, on the Gulf Islands where I live, we have this support group and we raise money in the simplest of ways, we don't get any government funding. We buy our groceries at the grocery and put our little slips into a box or we get credit for the food we eat and that's the money that we use. And if somebody needs to go to a meeting, that money goes to them. And there's no – there's no arguments, and if there's nobody that needs to do anything special, money just gets divided up between fourteen people, and if you feel like you don't want to take it, you don't have to take it, but everybody is given an equal share. And so, it's just a really beautiful way of using limited resources in a nice way. And that money was the kind of money that helped us to get the kind of respite that we needed in the early days. So, it did provide the money that we could use to get supplements when we needed them when that program at PWA stopped. We could get them by using this money that we got from grocery slips to get the extra drugs that we need, and stuff like that, so it was great. And people just help each other. There's just an awareness that we're so privileged in being able to wear shoes and socks and everything that we've got, sweaters, that we are willing to share. And just the way that you were talking about sharing with the homeless people, Char. It's just that kind of stuff that we're getting way better at as a community, I think. It's not as organized and we don't always get together for events, and stuff like that, but I think people do care about each other. And that's—it's a visceral kind of caring, it's not a saying I love you or something like that, but deep down, I think that we really do love each other.

AH: So, how's your perspective on the whole business changed over time?

P: My perspective. Ohhhh.

AH: You've gone from keeping it secret to being quite active.

P: Yeah. I think my perspective has changed in that I understand a lot more that we all come from different places. And so, sure, I might be ready to go out there and tell the world that I'm HIV-positive, and not worrying about having my face blacked out and my voice changed, or anything like that. But not everybody's there, and I respect that, and I understand that, in a way that I didn't initially. I think I felt like a bit of a con artist not telling people something that was so important to me in the early days. I don't think I was, I think what I was doing was I was protecting what little piece of dignity I had. I didn't want to lose that. And so, I was protecting it until I was ready to stand behind myself and be HIV-positive and out there. And I'm happy to support people wherever they are now. The most fun I think I have is in facilitating the body maps, where people start to explore where they are themselves and their ability to go in, and see how far in they can go before it gets really uncomfortable, and then just wiggle their way out again and share what they want to share. And not share what they don't want to share. But it's pretty remarkable, because we take a group of eight women that don't know each other, for the most part, put them in a room for three or four days, and by the end of it, people are sharing the most intimate concerns that they have around HIV and disclosure and the laws. And their frustration with not understanding how the law can be so crazy. So yeah, I feel now that I really want to go to jail. And maybe it's for not disclosing my HIV status, but I doubt it, I'm not there. But for something, before I die, because there's so much injustice in the world that I'm ready to stand up for it, and be the one, or one of the ones who doesn't draw the line there because our society does. Because our capitalistic structure doesn't care about Indigenous rights and pipelines. I wanna be able to be strong enough to get there, and I'm not there yet, but one day I think I'll be the little woman tapping my cane at the logging truck, or whatever it is, to get arrested. Yeah. Because I do think there is injustice out there, and finding it and standing up against it is one of the things that we can do as a group. Or as individuals.

AH: What the—again changing it a little bit—what is your perspective of the healthcare community now? How have they changed, and what advice would you give them?

P: Well, when it's really good, like Oak Tree, don't change, but that's impossible to do because they're falling within a system and they have to make some changes and see people less often, and offer few – fewer services. But I think that recognizing that people are whole people. Mental health is one of our bigger components to health. Without mental health, we don't have physical health. Without feeling comfortable about where we are in our lives, we haven't got the ability to sleep, which is really, really important. To eat well, to relax our bodies from time to time. All of those things are really important to health care. I think taking the time to really check in with people and see where they are, and where they might be holding back in sharing information, is more important probably than the areas where you can poke their finger and find out, you know, what's going on with their blood sugars. It's a lot more important to find out what's going on with their heart, and with their soul, and with their ability to feel comfortable in their skin, than it is a lot of those details. And at the same time, I think those details are important too because I think looking at people living with HIV, I think things can still happen quite quickly. And so, staying on top of the physical, mental, emotional, spiritual stuff. And there is a spiritual component to healthcare that often gets ignored. So, I think taking the time to check in with people and see, do they have a spiritual practice, what does it look like, is there anything you can do to support that as a healthcare provider? Those are things that would be helpful.

AH: You referenced Julio Montaner earlier—

P: Yeah.

AH: --has he evolved?

P: Oh yeah, Julio has definitely evolved. But Julio is still very focused on himself. And—and I said that this could be public—but I think that's a piece of the scientist that is there. So, he's done a lot of work, but really, the work he's done is through the bodies of people who live with HIV. And I don't think the reciprocity is there. I would be really happy to see Julio honor all of the people whose lives have led to the results that he's able to use in his research. But he is a lot more approachable, and he does ask entirely human questions instead of entirely medical questions. And I do respect that that's a difficult thing for somebody to do—to make those changes when you're living in a world of academia and scientists, and competition is still rife in that world, I'm pretty sure. So, he doesn't have the benefit of having a cozy group of people to snuggle up with. Yeah. Yeah, Julio's changed. And my doctor's changed. My doctor's decided he's done, he's finished. He's retired. So, some people have changed because they need to step out, and some people have changed because they need to step up. And I think Julio's stepped up.

AH: Any advice for future generations?

P: Oh, little ones, the young ones. Well I—don't give up, don't ever give up, and one of the things that I regret in my life is not having kids. So, for young women that are HIV-positive, don't let HIV stop you from having kids, 'cause it will also stop you from having grandkids later on. I think it's a complicated world out there. Bless everyone who's having kids, because I wouldn't want to bring a kid into this crazy world that we're leaving people with. It's a bit of a mess. But I don't think that should stop us from thinking that there is hope, that there is a future for everyone, whether they're HIV-positive or not. And stand up for what you believe in, and get the support of some of your elders if you need. I'm willing to stand behind you if you need somebody to stand behind you. If you're doing what you think is right for you. I think our own barometers are the best judges of what is right and wrong, not necessarily the courts or the medical system. You'll know when it's the right time to take medicine, and you'll know when it's time to stop.

AH: Is there anything else that you'd been thinking about, that you'd—that has not been covered? You covered a lot of the questions without my bothering to ask them.

P: That's great. I had a sneak preview at some point ages and ages ago. I guess one of the things that I think is really important is that we don't lose this old stuff. I'm really glad that this project is taking place, because we do forget. I forget names, I forget moments, I forget some of the people who were really helpful early on. They're the people who made it possible for us to be here now. And a lot of them died. A lot of the early pioneers in HIV and AIDS are not here today to interview. And a lot of us who did live by some incredible miracle—and I'm going to talk about that a little bit too—by some incredible miracle are getting forgetful, getting a little bit slower. We have a lot of stuff stored up here and it's not all easy to recount and reconnect to. But I want to talk a bit about miracles and believing in miracles, because when I was really, really sick in the '90s, in the early '90s. I was put on hospice care. I had diarrhea for two-and-a-half years, and I was really, really thin, and really unable to gain weight, and so I went into the hospital and they checked everything. I think I had two colonoscopies in ten days, I had a bone marrow tap, all kinds of tests. Couldn't figure out what was going on, so they sent me home. And I decided that I was gonna get in a wheelchair and go to Belize. Because [name], my partner, loved to snorkel and dive, and I wanted us to have one holiday where he had such a good time before I went. So, we went to Belize, and I really could barely walk. And we got there, and I rested, and I read, and we ate rice and beans and fish. Really simple food. We were way, way out there. I had no idea where we were going—friends from Oregon had suggested we go to this reef, off-shore, and it was about eighteen miles off-shore. So, we were way out in the middle of nowhere. And I got stronger everyday. And I think reducing stress is really important, believing in yourself, and being in a happy environment, is really critical. So, if you love sunshine and you love the ocean, figure out a way to get to the sunshine and the ocean. Or figure out a way to make miracles happen, because that's where the change really, really happens.

AH: Nice place to finish.

PF: Yeah. That's it.

AH: Thank you.