"HIV in My Day"

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Interviewee: anonymous (P); Interviewer: Charlene Anderson (CA), Art Holbrook (AH)

Interview anonymized at participant's request

CA: It's happening we're live.

P: So should I be looking at you or at looking at the—

CA: Look at me. Well it's up to you. I'm not that hard to look at I don't think. And what's your name? Tell me your name, and where you're from, etcetera. Yes.

P: I'm [name] and I live on Salt Spring Island. Previously from Vancouver, and yeah.

CA: So icebreakers here, tell me about your connection to Vancouver?

P: To Vancouver?

CA: Well actually to your newest residence I guess, to Salt Spring. And then we'll go backwards.

P: Oh I moved here about a year, just over a year ago. And I just wanted to get out of the city that was getting crazy busy, more and more. So my partner and I decided to move over here partly because my brother lives here and a few friends live here, and just be closer to nature, that kind of thing. And we love it.

CA: And what about Vanc—what's your connection in Vancouver?

P: My connection?

CA: Yeah.

P: I grew up there. And uhm, so that's my connection.

CA: Born and raised in Vancouver.

P: Yeah my grandfather was born, uh there's the building is still there down on Granville Street. Right downtown, yeah it's a 7-11 now but it used to be Webster's General Store, and that's where my grandfather was born. So, several generations.

CA: Cool. I know where that is. When you were in Vancouver, did you identify with any different communities or cultures when you were growing up there?

P: Uhm, different communities or cultures…

CA: Like did you belong to any different communities? The LGBT community, uhm any different kinds of communities?

P: Oh well yeah. Oh yeah. LGBTQ. Uhm, eventually when—

AH: Excuse me, would you say those things in full sentences because—

P: Oh yeah. I didn't know if this was just warm up or if this is actually stuff they're gonna use.

CA: It's—nah we're doing it, we're doing some little ice breakers.

A: We don't know whether it's going to be used or not, but at least we have it. So if you would say, you know, I was part of the LGBT community in Vancouver.

P: Yeah that's why I said that 'cause I—

CA: We have to have a few of these, we're not professionals.

P: No you're good.

AH: Well I used to be. I used to be.

CA: He used to be.

P: And I know about doing that stuff too 'cause I've done public speaking. And of course, but I thought it didn't matter because it was just fluff before we're getting into the real deal.

AH: Well it's probably going to be just for fluff.

P: Especially now.

AH: Yeah, we're recording all this nonsense.

P: Well you're going to have to edit out Charlene's constant giggle. But she's having fun, so that's all good.

CA: Always. Yes, so what communities or cultures did you identify with, growing up in Vancouver?

P: I identified—as a kid, just uhm a kid. The kid culture. As I grew older I uhm, yeah I came out as a lesbian I guess when I was about twenty-five, something like that. So then I did become part of the queer community, or lesbian-gay community at the time, before we got more and more letters. And then I uhhh lived and travelled quite a bit in my youth, so I have lived in a few other places briefly. And then I went back to Vancouver, I always considered that home. And I still feel very connected to Vancouver, but happy to be here on Salt Spring.

CA: Uhm so—and now we're going to dive right into HIV and AIDS content—what did Vancouver look like before the HIV and AIDS, before HIV and AIDS came on the scene?

P: Specifically the community or?

CA: Specifically I guess the gay community, yeah.

P: Uhm, let's see well when I came out it was about nineteen-eighty-seven, eighty-eight, in there. So HIV and AIDS was already in full swing, it was already happening when I came out. So I don't know the queer community pre-HIV really. But I do remember being in high school in nineteen-eighty-one, it was my graduation year and that's when I first heard of HIV, it was in the news. And that's when a story came out saying gay men are starting to die in New York City and San Francisco. And so I did notice it and I was like oh wow, what's that all about. And then it also, they started talking about African and Haiti, uhm hemophiliacs, etcetera. I did end up going to Africa in nineteen-eighty-four, and I remember some of my friends saying, 'oh, what are you doing going to Africa, you might get AIDS. You know, watch out.' And I was like oh come on you people are blowing it out of proportion, and that's happening just in Uganda, and I'm going to West Africa so it's not happening over there. You know, that kind of thing.

CA: Oh well that answers like how did you hear about AIDS and what was your initial reactions. What was your initial reaction when you first started hearing about it?

P: I was concerned. And I was like, you know it's always kind of a bit of a shocker when there's a new serious terminal illness that just kind of seems to come out of nowhere. And that's what it seemed like, it's like one day it wasn't there and then it was suddenly on my radar. I didn't have any gays or lesbians, well it would be gays, gay men mostly in my—actually I did have one gay man friend around shortly after that, so it did become a little bit of a oh, you know, what are you doing to—are you concerned, I would ask him. So I was concerned for him. But I didn't think it was anything that would ever cross my path. It was just like very far removed from me personally.

CA: So at the very beginning then, did you have any sense of severity? Or get anything from the news about how big it was going to be, or?

P: No, definitely not. Because I'm always, I'm a bit of a cynic with the media. And I always thought oh they blow everything out of proportion, they dramatize it, it's like. Yeah I felt badly for people who were affected but I certainly didn't think it was going become such a big huge problem that it became. Especially not affecting me directly. I was concerned about my younger brother, because he's gay. So I was quite concerned about him, but he reassured me that he had safe sex practices etcetera, so I didn't continue to worry about him too much. And he did remain HIV negative throughout all these years. And then I was the one became positive, which was very perplexing to both of us. Kind of ironic.

CA: That's what I was going to say, the irony of it all. So how did you learn about HIV/AIDS, was it—you know you were saying that you were cynical about the news, and yeah, is that mostly where you heard about it from?

P: Yeah, and then when I did venture to Africa I learned a little bit more at that point. Either through the organization I went with to Africa. And then when I came back and that's really when I came out, so then I became part of the gay-lesbian-trans community, and so it was on my radar a lot more. And I went to a protest or two, protesting Bill Vander Zalm and you know the lack of action that was being taken here in B.C. So I went to a protest. Oh, one of my co-workers in about nineteen-ninety-two or so, uhm he was gay and he became HIV positive and he passed away. So that was huge deal in our, in my workplace. It was just a small workplace of ten people so that impacted a lot of us. And he just—actually he and I were both in the closet, and once he got sick then we both came out of the closet and it was very supportive in terms of that. But still I hadn't been diagnosed yet. But shortly after that I was.

CA: So going back to when you were in Africa, when you came back from Africa, did you gain lots of new information and insights about HIV and AIDS while you were there?

P: Probably.

CA: Probably?

P: Oh while I was there no. No, I was in West Africa, it wasn't on anybody's radar. When we were there nobody was talking about it, nobody was affected or infected as far as I knew. And then also after that in nineteen-eighty-seven I went to Lesotho in Southern Africa and again it was on nobody's radar down there even and you know, it just hadn't really, I mean I'm sure there were people at the time who were sick from it and dying from it, but they were not getting diagnosed.

CA: It wasn't really a thing yet?

P: No, it was still really central Africa where that was a thing.

CA: Oh wow. So how did you respond to the AIDS crisis personally, even before you found out you were positive did it have any impact on how you led your life, your sex life, anything?

P: Well yeah what I just said, I went to protests I was—by that time and after I came out and everything I was really concerned, it became a real issue in that community. So I was, you know I was pretty horrified at the response—or lack of response—from the province and that there was talk of you know, isolating people. What's the word for that—quarantine. Yeah there was talk of quarantine at one point that really outraged us. I think that's what really sparked me to go to that protest. It was out at Fantasy Gardens, which was Bill Vander Zalm's it just was—anyway it was out there I remember it really quite well. A really good turn out protesting Vander Zalm and his yeah, lack of response.

CA: Politics, yeah. So part of the question here is about your own sexual behaviour. Did anything change around that when you started becoming aware and involved in the HIV/AIDS movement? Like with drugs and alcohol, or anything like that, did it have any impact on any of that? On your partying?

P: No I wasn't using, I never have used IV drugs so no, not to do with drugs or alcohol. In terms of sex I was in the early eighties, I had sex with a few men, not very men like you can count them on one hand. And I was a little bit concerned at that point and I knew that condoms should be used, and they were. So other than that, no.

CA: So you looked after your own sexual health and yeah, all that kind of stuff.

P: Yeah I mean there wasn't very many encounters. And then once I came out as a lesbian then I really thought no there's no—I mean there was talk of oh you should use dental dams. And I did consider that, actually did try it for fun more than anything because I thought no this seems very far-fetched or whatever. And the dental dam was not, aside from being a good laugh, it was not something that I believed we needed to use. And I only used it that one time just to give it a try. But I really did believe that no this is—once I learned a little bit more about transmission I thought no, this is very low-risk for lesbian.

CA: How did you learn about transmission? And about that, because I know there was periods of time that you know, it was everybody has to use safe sex, absolutely everybody because you can catch it from anybody. So how did you educate yourself?

P: Uhm, through the queer community really. There was lots of information being distributed everywhere, and uhm, I guess that's the main way. Talking to people. The women—my partner at the time worked at the women's health collective, and she was a nurse. So she had a lot of access to information. So that's mostly how.

CA: How did your identity impact your experience of the epidemic? So did any aspects of who you are as a person shape the way you experienced the epidemic? They ask about race, class, gender, education, employment status, that kind of thing.

P: Uhhmm..

CA: So do you think maybe okay so, the way that I see this question is, do you think because you were part of the queer community that that had an impact on how you—

P: Can you just re-phrase or read it again ?

CA: Okay. Did any aspects of who you are shape the way you experienced the epidemic? Your gender, your race, like what kind of things. Your education, your class, your sexual orientation.

P: Yeah. For sure my sexual orientation.

CA: And your age, or yeah.

AH: Expand.

P: Pardon me?

AH: Expand on that.

CA: Yeah, could you expand on that a little bit?

P: Well yeah you can keep asking me questions. But yeah, because I had gay men in my life then and, especially my co-worker who died and then my brother who was gay and I was worried about him. And I actually, for awhile there he started getting really thin and I thought, oh no, what if he has HIV. I just was thinking, I jumped to a conclusion that it might be. And uh, but yeah he did get tested and he wasn't HIV positive. But uhm, yeah the gay community for sure. And because my partner was a nurse at the time, and she was actually working at St. Paul's in a Medical ward, that was before they had a specific ward for people living with HIV. So she was treating mostly gay guys with HIV, and a few women, and so I was hearing about it a lot from her actually. And she was very impacted, like front line right? As a nurse, and having patients pass away who are you know, in their twenties, and tragic. Yeah that was actually, uh, yeah. That was uh, yeah.

CA: That makes me want to cry.

P: Yeah.

CA: Very impactful. Yes. I guess that's what I was trying to get at. Sorry. So you were front line, basically?

P: Yeah. I kind of forgot about that it was so long ago. But yeah, I kind of forgot that she would come home and somebody had passed away, and you know, and it just felt like such a huge tragedy. And especially as lesbians we felt like allies to our gay brothers and this was happening around us. And it just seemed kind of unstoppable at the time. I think I'm going to get a Kleenex.

CA: Kind of like a freight train.

P: I don't even know where I have them because I don't cry that often.

CA: I do.

P: Yeah when you start really getting into talking about it, it's like oh right, that was a hard time.

AH: You're hardly the first person to—

P: Oh I'm sure.

CA: I'll take one too.

P: Okay.

CA: So we're going back to this quest—

P: Oh actually can you pass me one of those now I left them over there thinking oh you're going to need them more than me. But I'll probably need one too.

CA: So this leads us to, how did the epidemic manifest itself in your life? You know you were living with someone who was on the front lines so you basically were too.

P: Yeah.

CA: Can you expand on that a tiny bit?

P: Uhm okay, you mean repeat some of it?

AH: Well how did that affect your relationship with your partner? She was directly affected by that.

P: Well I uhm, how did it affect my relationship with my partner? Well I had nothing but compassion for her and for the whole situation. So it didn't really have a negative effect on our relationship, if anything it brought us closer because uhm, of you know, me supporting her and yeah we were very, hmm, very bonded and we cared a lot about the guys who were sick and who were dying. Yeah and then I had my co-worker, and that really was very difficult too. And we went to his memorial, and stayed we in touch with his partner afterward for quite awhile as well. So I'd say yeah it was a very tough time but we stayed together, it really bonded us I think, just going through that.

CA: So it had a very big impact.

P: She would actually be a good person to interview for this, actually. She and her partner.

CA: Yeah, hopefully they have.

P: I don't think they have actually but I can pass on some contact info for them. Because both of them—she's in a new relationship with somebody who's also uhm, well David Birch. He was a doctor at Oak Tree.

CA: Oh yeah, okay.

P: Yeah. They would be very—I don't know if he would want to do it actually, because he was, anyway he was very impacted over so many years, I don't know if he would want to do it or not. But she would I think. But that's an aside.

CA: I am going to pass that along. And you've answered all of this question. So, yeah what impact did it have on you, and your partners, friends or family. Were you seeing the epidemic—you were seeing it at home in your social circles, so it did touch a lot of corners of your life.

P: We were also watching the Doctor Peter diaries as well. It was weekly. We watched every single one. And you know she was really the initiator of that, and she you know—well both of us were—but we thought wow this is bringing it really into the mainstream. We thought that was a very positive thing. I mean also tragic but it was needed, that the general public needed to have a face to HIV. So I thought Doctor Peter was of course very courageous and he was you know it was quite moving uhm, seeing him deteriorate. It was also very sad, very difficult, uhm yeah but it was, I just appreciate him so much for doing that.

CA: It was hugely impactful.

P: I'd forgotten about that too.

CA: You have a lot of history.

P: Yeah, well any of us who have been—anybody once we're at this age does, but with HIV yeah. And a lot of it was before my diagnosis, all of this was before my diagnosis.

CA: So it had an impact on you before it even impacted you, physically.

P: Oh absolutely.

CA: Wow. Huh. Uhm, what did government and medical responses to the epidemic look like?

P: Hm, the government and medical responses to the epidemic were hmm, well the medical was a little better than the government, I think. Yeah the government as I already spoke about, the Bill Vander Zalm government a very right wing and kind of, well not kind of that government had their heads in the sand around it. I think they were just hoping it would go away, and basically didn't take much action, at the beginning. At all. They eventually did, it was still very minimal. I think the medical response was actually remarkable. In Vancouver. I won't speak to rural areas, whole different story. But in terms of you know and because of my partner working at St. Paul's I was exposed to that which was probably the best case scenario, in B.C. anyway. For people. You know I think there was still a lot of, of course stigma, fear, that kind of thing. But I do, I know a lot of the nurses from the early days and I think they rolled up their sleeves and they just went above and beyond in caring for patients with HIV. I think the universal precautions came along pretty early, and I'm sure earlier than that. You know I'm talking from about nineteen, the late-eighties now, so I can't speak to the very early eighties because that wasn't on my radar exactly, very much. But towards the later eighties that's when I feel like it was uhm, and the numbers were climbing of people who were getting sick and dying. And that's when I feel like the medical community in Vancouver really went above and beyond, in general.

CA: And what did they do? What was the response?

P: Well I felt there was great—I felt like there was great, because I knew a lot of nurses through my partner, I felt like there was just a really remarkable compassion, which in turn led to I think good care from nurses anyway. And social workers, and those kind of folks. I think there were lots of support circles that were created, uhm maybe a little more into the LGBTQ community, lesbian gay bisexual transgendered, I can't say that one out every single time.

CA: Yeah LGBTQ community is good.

P: The queer community, I'll just say that. Yeah, a lot of the support came through the queer community maybe more than the medical, I think the medical community people were just up to their eyeballs with trying to just take care of people medically. But I know, I went to a lot of the early BC, they were call BC

AIDS conference. I went to a couple of those, my partner was going and she kind of snuck me in, and said "you've got to come and see this session, and you've got to come and check this out." There was a lot happening, and I think those conferences were a really good place for people to—you know like any conference—but to uhm, I don't know to connect and to find—

CA: Were they just like medical conferences or were they open to anybody?

P: Oh no they weren't just medical. It was a big component was how to support people who are sick and dying. You know really. Because in those day it wasn't so much saying oh people living with HIV, it was people dying of HIV back then. Really. And then as we got healthier and I think it became more of a living, but it was really, it was literally a death sentence back then. It really was. A terrible time.

AH: Can I intervene with a question here. Uhm, we've heard stories of nurses, doctors, care people, sort of pushing them off and you know, pushing trays into the room or that sort of thing. Did you experience or hear about any of that sort of thing? That sort of we don't know what's going on here, we're scared of them, well [inaudible] send their food, or did people really rally?

P: I think people really rallied. But like I said, I don't know about the very early days. Like the early eighties. I mean uhm I guess when did HIV, when they discovered what the virus was? I guess was that eighty-five, around then? So I'm more my experiences, you know I was in Africa around then. And then when I came back it was like eighty-eight, eighty-nine when I was with my partner and then she was uhm, you know really in the thick of it. More like nineteen, first few years of the nineteen-nineties. And at that time, I feel like there wasn't as much, not at St. Paul's Hospital, downtown Vancouver. You know a lot of the staff there were connected to the queer community as well.

CA: By virtue of how close it was to?

P: Yeah. But I feel like it was uhm, that's where I feel like it was uhm, I think people did a very good job of supporting people living with HIV. From my perspective. I know there are those stories, but maybe that was earlier, or maybe it was just stuff I wasn't aware of.

CA: I think too that maybe would've been something that might have happened at Vancouver General Hospital as opposed to St. Paul's which was connected, so-well connected to the community by virtue of it's place in Vancouver.

P: And eventually I think the majority of patients living with HIV did go to St. Paul's Hospital. Not all, for sure, but I think that's—people knew that's where the most experienced doctors and nurses were, and so that was kind of the ground-zero in Vancouver.

CA: How did—what were your perceptions of the mainstream response to the epidemic, to the HIV epidemic?

P: Well I thought it was—you know that was a time when uhm there was of course a lot of homophobia and I think HIV/AIDS increased the homophobia, by a lot. I think it set us back, a lot in terms of you know, having more and more rights and yeah I think it sent more people into the closet. You know because for a lot of people they had to come out as both gay and HIV positive, or AIDS, and that was pretty heavy. You know I heard of lots of guys who were like oh that's when they came out to their parents and families was because they were dying. That's the case for my co-worker, his name is Geoff. And he had been very much in the closet, and then when he was sick and dying that's when he came out really. But yeah I think it really took us back into more, more and more of a place of fear. Yeah the stigma was so great against, you know, double-whammy against stigma against people living with HIV and in the queer community.

CA: Yes, I tend to agree with you. So how did your community respond to the epidemic, what actions did your community take? I know you've touched on it a little bit but was there uhm, you've talked a little bit about fear and stigma, did you witness cases of compassion and caring, like just in the general community?

P: Yeah absolutely, I think there were a lot of people outside the queer community as well, but mostly connected to either in the medical sense, or otherwise. Social services field or whatever. But yeah a lot of people responded with a lot of compassion, for sure.

CA: Other than the one rally you talked about, did you participate in any community grassroots responses? Besides Vander Zalm's Fantasy Gardens. Yeah what kind of things did you participate in?

P: Well a lot more after I was diagnosed, although I was quite sick at first, but once I was healthy enough and I got connected with Positive Living Society, or BC Persons with AIDS Society at the time, I did get involved in whatever activism we were taking, there was often activism aimed at politicians. Or you know fighting for more funding and that type of thing, and I participated in a lot of those protests.

CA: Awesome, okay and if so how did you become involved. Did you have any social or health-related experience prior to your involvement with HIV/AIDS work?

P: Sorry say that again?

CA: Did you have any social or health-related experience prior to becoming involved in the HIV/AIDS work—

P: Social or health-related experiences?

CA: Like any kind of social work experience?

P: You mean as a patient, or person living with HIV?

CA: No, no, before then. Like uhm, uhhh---

AH: Well I guess the health related, your partner was a nurse. But on the social side, what do you think?

P: Well there was kind of an overlap with her nursing and then because we knew a couple of people in the community so yeah the social, it wasn't like she was only focused on medical. She was very caring, and very political activist herself. So I don't know how else I can expand on that.

AH: You mentioned uh, protests there—what form did those take? Is that standing in front of offices with signs, or?

P: Yep quite a bit of that. Just walking around in a circle with our placards and chanting and yelling, that kind of thing for sure. Uhm, I didn't get ever involved in anything violent like whatever, throwing eggs or anything like that or jumping on you know—talk to John Posichenko, I'm sure he's been interviewed for this. He was like the number one activist who would do anything to get noticed and it was really remarkable what did.

AH: What else besides that did you do?

P: What?

AH: What other forms of protest did you, were there?

P: Uhm, mostly that was it, I'm trying to remember.

AH: Letter writing delegations?

P: Oh for sure, petitions, letter writing we did that kind of thing. Those were like the easiest forms of protest, I would think. And uhm, yeah that's about it really.

CA: Okay. Were you and are you involved with any organizations around HIV?

P: Yeah, I just mentioned Positive Living Society, or do you want me to call it by it's name from previously?

CA: Yes.

P: Okay so, uhm—is there are time where you're going to ask me about my diagnosis?

CA: Yeah.

P: Yeah that's comes? Okay. Because that was uhm, so—yeah I can't really separate the two that much because it was when I was—so yeah I was—I became connected to BC Persons with AIDS Society as soon as I was diagnosed. Like basically the next week. I just thought, okay I'm somebody who wants to find resources and get support, asap. And I needed it, I was in major shock and fear and you know I was just, my life was upside down and I need to reach out. So I went to BC Persons with AIDS Society right away and got support from them, and AIDS Vancouver, and the Positive Women's Network, all within the first couple of weeks of being diagnosed, and that was very important. Very important to me to get that kind of support.

CA: Tell me about your diagnosis.

P: Okay.

CA: Because I want to ask you more about those groups.

P: So I was diagnosed in nineteen-ninety-five, and I was still with my same partner, who's the nurse working in HIV at St. Paul's. So we had already been together for about eight years, and then this diagnosis came out of the blue. I got a phone call from my GP, one of those mysterious phone calls will you please come in and see me. And I thought what is that all about. So I went in, it was the last appointment of the day and I was just like, very perplexed. And she just laid it out to me and I was just dumbfounded, like nope, this is—this can't be the case. And I'd been with my female partner for eight years by that time, and I'd only slept with about you know, less than five guys in my whole life and I just thought no this does not make any sense. And of course right away I thought back to my time in Africa and it still made no sense to me. Because I—I had sex in Africa only once—anyway risky sex. Well and actually we used a condom, so it wasn't risky sex. But anyway uhm, so I was, I was very baffled. I just—and shocked. So I of course got another test to make sure it was true. And of course my partner was just completely blown away by this news and—but it—so it turns out it was true, obviously. And uhm after you know a couple of tests and I still don't know a hundred percent for sure how I got HIV, and it doesn't really matter, the fact is I got it. But it was probably either uhm, I had a gamma globulin injection in Africa, that's a blood by-product, and it might've not been properly done in a resource poor setting. It might have been that. It might have been that one time I had sex with a guy. And so it was a big mystery, but, it doesn't really matter and I don't even really share that very often anymore. Because it doesn't—well it's so long ago now. But at the time it was a pretty huge deal to try to figure—how did I get this? It was—you know I'm a lesbian and I thought I was in like one of the lowest risk groups, you know lowest risk behaviours possible. And then uh, so this really came out of left field. And the reason my doctor—I didn't go for a test—my doctor called me in because she—I had donated blood about I don't know, a few weeks prior. So it was the Red Cross that contacted my doctor. And my doctor contacted me. I'm glad it was in person and not over the phone, like I've heard some people get their diagnosis uhm, and my doctor was very good about it. I you know, not right away but awhile later I did think my doctor could've done a better job. She did miss—I had some symptoms, signs and symptoms that I went to her about. I had rashes, I had recurring yeast infections. You know I was eight years living with HIV without knowing it. And so I was starting to be symptomatic, and these were classic symptoms in a woman that I was having, and my doctor never thought to you know, get me tested for HIV. I don't totally blame—I don't blame her, I think it was an oversight but I don't blame her of course. Because she also thought, well here's a lesbian, and you know—

CA: Back in the day you were not a risk group.

P: Yeah, and we did talk about it in terms of groups back then.

CA: Yeah.

P: But uhm, so yeah that was unfortunate. I think she learned a lot that day. As did I. So like I said before, right away I sought support, but I stopped working right away. My health spiralled downward right away, because I had a lot of—well needless to say, stress—and also I became very full of anxiety. And I couldn't sleep, and I couldn't eat. I just was emotionally struggling a lot. So I think that shock of the diagnosis did impact my immune system further. And I right away—not right away—but within a few months I had my first opportunistic infection, which is called uh MAC. Mycobacterium avium complex, and that was systemic through my body. Then I got wasting syndrome. Then I at one point looked at the graph of my weight and was just like pffff it just really went down, really fast. And uhm so my—I was going to Oak Tree Clinic and I'm so grateful [sigh]—anyway uhm, grateful uhm—I got one—yeah [crying]—okay—I don't think about this stuff that much anymore. Uhm [clearing throat] where I was I—so yeah I got sick so quickly and I was referred to Oak Tree Clinic right away, and I just feel like that was the best possible care that I could get at Oak Tree Clinic. They yeah, they were just phenomenal. And both helping me manage this illness physical and emotionally so uhm, but so they said okay, you're wasting so you need to get a feeding tube and it was like—anyway so uhm because of the wasting syndrome I got a feeding tube and that was a game changer actually. I was then being treated for the opportunistic infection, and then as soon as I got that feeding tube—and they partly gave it to me—it was not—it was a high-maintenance thing to have. Like you had to have this tube, and you had to flush it out, and you had to hook it up to a machine and I got two thousand calories overnight. But because I was in a relationship with a woman who's a nurse, they thought okay, this is doable. And yeah, she really saved me. And that feeding tube really saved me. Uh, so as soon as my weight could come back up—you know I was quite skeletal—but my weight came back up and then eventually I got my energy back and then around this time, it was nineteen-ninety-six, ninety-six late ninety-six, then the protease inhibitors came out. But I don’t think they actually—you know people talk about nineteen-ninety-six and the conference—but you know what we—I didn’t have those pills in my hand until like ninety-seven really. So it took awhile. Yes they were announced the research was out but the patients here didn’t start—they started getting them in the U.S., but not here, in Vancouver. So I was in that first cohort of people taking the protease inhibitors. And I tried a few different ones until they started working, so the protease inhibitors combined with the feeding tube, and all of my self-care and support and love from friends and family and uhm, healthcare professionals, then that turned things around for me. Unbelievably. Not overnight. I would never say it's the Lazarus effect, you know like some people say. And maybe it was for them. But it took quite awhile, I had to be very patient. It took a long time to regain my strength, my weight turned around quickly but my energy took a long time. My CD4 took a long time to climb back up, so I think it was more like by nineteen-ninety-eight, ninety-nine when I felt like hey, maybe I’m not going to die imminently. Wow. I feel pretty good. I think I—and you know I went travelling, yeah it was quite remarkable. I felt like—I didn’t know it at the time that I dodged a bullet. Because I was still full of quite a bit of fear, probably until early two-thousands. And then—well I was still, even then, I think it still even took a little while after that to feel like hey, until we started getting news of hey we uhm—the meds got better and better and that wow, we have the same longevity that you know someone who’s HIV negative has.

CA: You’ve outlived what they told you you would live, way back when.

P: Yeah. So it took awhile. Yeah.

CA: How did your friends and family react to your diagnosis?

P: I got a lot of support and love after my diagnosis.

CA: Yeah?

P: Yeah I didn’t have any uhm, nobody close to me was anything but supportive. So I’m very grateful for that. You know people were equally as surprised as I was. But I was never shunned, or—I did not experience any—I’m lucky—I did not experience any stigma from close friends or family. Yeah I feel very grateful for that as well.

CA: And what about the reaction in the queer community? Like in the lesbian community, was there one?

P: In my circle of friends that were, a lot of them were lesbians. They really rallied around me. They created support circle, bringing food, all that kind of thing, so I felt very supported by my friendship circle.

AH: Excuse me, are you sitting on my sweater there?

CA: Nope.

AH: Where’d it go?

P: Oh we could stoke the fire again but, if you have a sweater that’s—

AH: I don’t know where it went. There it is, you are sitting on my sweater.

CA: It’s nice and warm.

AH: If you don’t mind me asking, did it affect your relationship with your partner?

P: Uhm, my diagnosis? Yeah well—

CA: And subsequent illness.

P: Uhm, so of course when I was diagnosed my partner obviously got tested right away, and she was HIV negative. And uhm she—actually it was quite remarkable, it bonded us. Just like the experience of when she was working at St. Paul’s, that bonded us, this bonded us even more and she was really there for me. And she—when I was at my sickest, when we thought I was heading towards death, and I had a life insurance policy through work that I cashed in part of it, in order to have better quality of life for my last years, so my doctor you know signed all these papers and wrote letters to say he thought from his perspective I had a year or less to live, but I wanted to access those resources. At the time, so partly why I did was my partner at the time, she went on a leave from work to take care of me. And that was just hugely uhm, you know, it was just an amazing thing that she did for me, to take care of me every single day. And she was there twenty-four-seven for me. And not to mention a nurse with HIV experience, right?

AH: Is this thing recording?

CA: Mmhmm.

AH: Are you sure?

CA: Yeah. Got I hope so.

AH: Its just—is the little red button supposed to be big or small?

CA: Small. Yeah.

AH: It is small then, we’re good. I just never remember that.

CA: No, no we’re recording, it’s all good.

AH: I know you checked before.

CA: Everything’s good, all systems go.

P: So you had asked me a question, about my partner?

AH: Well you’ve answered it, that she was supportive. And that didn’t affect your relationship, or it bonded you closer.

P: Yeah I mean eventually that relationship did end. Not until about two-thousand-and-two, when my health was very stable by then. But we remain close to this day, going through that is something that really connected us, and yeah, we’re just friends to this day. But I do think she should be interviewed for this, because her experience as a nurse plus as a partner of someone living with HIV.

CA: Yeah I’m going to put that out.

P: Yeah, she would be a very good person to interview about this.

CA: I've never—no that's not true I've met her once.

P: Oh did you?

CA: Long time ago.

P: Yeah and she actually was a nurse for Marguerite. At St. Paul's, that kind of small world thing.

CA: Very. We are quite a little group. So what kind of things did you do with the organizations you were involved in?

P: Well first uhm, for the first few years after my diagnosis I was simply a recipient of services. A lot of services. I was very well supported. But the most significant thing in those early days was going to retreats. Because I needed a lot of emotional support from other people living with HIV. And at the time, my first retreat I was the only woman there. It was me and the gay guys. The wonderful gay guys. And that was at Bowen Island, it was probably nineteen-ninety-five, only a few months after I was diagnosed. And that was a very important experience for me, to help me process and cope. And even have a lot of fun. And I met some guys there who remain good friends of mine to this day. So that was very significant for me. Just uhm, that kind of connection. I also was accessing things like tai chi, yoga, relaxation groups, all of this was very important for me because of the anxiety that I had. And I think when I got this diagnosis what it did was it sparked some anxiety and emotional challenges that I had anyway, and it kind of brought it all to the forefront. So I proceeded to do a lot of therapy, and it really helped me and all these organizations really helped me in my healing that wasn't just about HIV, it was about other stuff from my past. And that was a gift really. And to this day I realize wow I had all this access to all these amazing supports, you know from the emotional side of things for me, that was just—it was a gift that I was able to heal so much, from stuff that wasn't even HIV—direct HIV related. And of course HIV exacerbated everything terribly. So then Positive Women's Network was also a very important place for me in those early days.

CA: And what was the Positive Women's Network? What did they do?

P: The Positive Women's Network was an organization in Vancouver that supported women living with HIV from all across British Columbia. So to have that women-specific support was important, however I—it was interesting 'cause uhm, it was very valuable however sometimes I felt more supported, or I got—because of being a lesbian, I felt like the people with HIV that I was meeting through uhm, well through Positive Living or BC PWA at the time, it was in the queer community. So I felt very connected, I felt like I could really be myself with the gay guys. And with Positive Women's Network it was more the straight women's community, where I did meet some fabulous people who are also good friends of mine today, but at the time, sometimes I felt like a bit of an outsider. Like I was the only lesbian around pretty much in those early days. And so I felt like I didn't always fit in, you know, ironically. But that was good experience. And then from there I ended up having opportunities to volunteer, which I did extensively from about early two-thousands on, and I was on the Board of Directors for the Positive Women's Network. I became very involved with the treatment information program at BC Persons with AIDS Society, and that was an incredible opportunity because I was interested in the science of HIV. And I wanted to know what's happening in my body, I wanted to understand it. I didn't want just my doctor to you know, brush over things and I wanted to know—I wanted copies of my bloodwork, I wanted to understand what was going on, I wanted to study up on myself so I could really—I felt like knowledge was power, and that if I can understand this I can take care of myself as well as I can. And I uhm, I did—so in that role I was a peer counsellor for other people that had treatment questions. Because back in those days the treatments were not that effective, and the side effects were enormous. And myself I had some side effects that have lasted to this day. Like long-term side effects. Changes to my eyesight that I still live with. And uhm, other changes, oh there's another one. Oh, I had a terrible—rare—I've had some very rare side effects like a rare anemia where I needed blood transfusions. I was dependent on blood transfusions for a year, and that was a side-effect of a drug called DDI. So I felt like with treatment information program I was supporting other people to understand about treatment and HIV. But at the same time it was helping me.

CA: You were becoming your own advocate.

P: Even more so. And I went to so many conferences and learned a lot about the mechanics of HIV and of treatment. And also not just uhm, you know western medicine treatment but I was also learning more about complementary alternative therapies and that was a huge part of my healing as well. And of treating HIV. And treating my anxiety and other issues that were arising. So that was—I'm very grateful for that experience with treatment information it was uhm—I met great people, I got to go to lots of interesting conferences and uhm, it was stimulating. And I needed that, because I had stopped working. You know I was working up until I was diagnosed and then as soon as I was diagnosed, that was it. Art!

AH: I'm nodding my head yes.

P: Do you need a cup of coffee or something?

AH: No I don't drink coffee. I'm sorry.

P: Okay I better try to be a bit more riveting.

CA: I'm riveted! I'm learning so much more about you, it's fabulous.

P: No but is my tone, am I just like monotone or something?

AH: No, you're fine I'm just nodding off.

P: So this is Art just having his late afternoon—

AH: I do that.

P: Okay, I'm not boring you to death.

CA: We a had big lunch before we got here, I went to the treehouse. I just had soup, I'm here.

[inaudible]

P: I'm boring the guy, he's falling asleep.

A: Oh another boring story.

CA: So big question, were you—so you did—

P: Feel free to go for a walk seriously if you don't. I won't—no I really mean it.

AH: I do want to be here, I'm sorry.

P: Well I'd rather you go for a walk than falling asleep. Really.

AH: Yes it's fine, that's fair.

CA: He can for around Bishop's walk, check out the properties.

P: There's a really nice view down the road.

AH: It's a lovely property.

CA: So uhm, did you provide any direct care to people that were positive?

P: Direct care?

CA: Direct care, uhm—

P: I'm very literal.

CA: You're very literal. Okay oh, here you go—what role did lesbians and feminists play in the—in the—

P: I think I kind of spoke to that, did I?

CA: You did a little bit. But I know from other people that uhm—the lesbian community were big allies for—

P: Well like I said in the early days my partner and I, because she was directly working in the field of HIV uhm, we both became allies, and we both cared deeply about was happening and we were, I think and I witnessed other lesbians being allies in a not just one on one with people but in an organized way as well, through probably an organization like the Gay and Lesbian Centre in Vancouver. There were ways—women wanted to volunteer and support and help the, mostly it was gay guys right then, but of course there were a lot of injection drug users. More and more being infected, more and more as time went on, like later eighties. So that community as well, but I think lesbians were particularly moved to volunteer and support the gay men's community.

CA: You did speak to that a little bit, yeah. So how did the community deal with the intense burden of care and support? Did you or caregivers experience fatigue or burnout?

P: Sorry, how did the community?

CA: Yeah uh so like there were a lot of people dying. How did you interpret people dealing with that? How did you deal with that, with losing people? Was there burnout and—

P: Absolutely.

CA: --accumulated grief. What did people do? What did you see people doing, or what did you do yourself to help deal with that?

P: I think there were lots of support circles, there was through Friends for Life—oh and Friends For Life is another organization that I accessed a lot of support from. Just having a massage. Somehow, when I was at my sickest, being on a massage table and having a massage was a brief time, an hour, where I actually felt good. Like physically. And I could, I think it was very much physical, emotional connection thing where I was able to relax. And my anxiety just lifted off of me. And Friends for Life was the only organization providing that free of charge at the time. This is well before other organizations did that. And I was at Friends for Life before they were in the house where they are now, like it was an apartment down in the West End, just a little apartment. And I would go there for massages every week. And the guy who gave me a massage was HIV positive. And that was important to me to have—especially somebody who was relatively well and healthy, that gave me a lot of hope. And then wow, he's living with HIV but he's able to do massage therapy as a volunteer. So I was getting peer support and a massage at the same time. It was so valuable. And I went on a couple of—I learned to meditate, and I went to a relaxation group where we did this really deep relaxation. Those things all saved me, they all contributed to, I think, improving my health vastly and just helping me turn that corner from going down the road to dying to you know—it was the whole combination. It was the meds, it was the feeding tube, all of these complementary alternative therapies like the massage and the tai chi, anything to bring down my stress and anxiety. It was very healing.

CA: So what was—

P: I went off track there for a bit, sorry. Suddenly I remembered Friends for Life. That was important.

CA: Well what was Friends for Life, I don't think everybody knows. Do you know what Friends for Life is, have you ever heard of it?

AH: No I don't think I have.

CA: What was Friends for Life?

P: Well it still is. Friends for Life is an organization created in the probably late eighties—actually it was created right around—actually more like, maybe around ninety-three, ninety-four Friends for Life started up. And it was simply to support people living with HIV with complementary alternative therapies. You know, massage and herbal—you could get an appointment with a naturopath or an herbalist or acupuncture. Oh I went to an amazing acupuncture group, this is history—back in uhm, yeah the well it was mid-nineties for me when I was I diagnosed I heard about an acupuncture group that was not free of charge but very low-cost, like ten or fifteen bucks a session. And it was group acupuncture with a doctor named Sunny Lee. And it was hugely, he was hugely generous. He uhm, provided this for—it was usually about ten of us there. It was again, all gay guys and me. But I loved it. And so we'd all go, it was at a church for awhile, then it was at somebody's house in the living room. And we'd just lay on the ground on mats, and stripped down to our underwear, and then doctor Sunny—well we didn't call him doctor—Sunny Lee would come around and poke us with acupuncture needles and we'd all lie there. And we would have laughs, we would share treatment information, sometimes we would cry. It was a support group. It was not intended as that at first, it was group acupuncture. But it was amazing, an amazing experience. There's only two or three of us alive who are still around to remember it. So hardly anybody I come across knows about it. But it was an amazing gift from this Chinese medicine doctor, Sunny Lee. He would be another good person to interview actually, he'd have an interesting perspective. Because he did it just out of his care and you know, he was just charging only very minimal just to cover some of his costs, but certainly not what he really would be earning as an acupuncturist. Or Chinese medicine doctor. So that was very great experience really.

CA: That's very cool, I like that.

P: Yeah, I got so much support and yeah I just, I looked forward to it everyday. He also prescribed herbs and stuff like that.

CA: So let's see here—

P: Oh wait I didn't—did I finish saying about Friends for Life? Oh yeah so Friends for Life—oh no maybe I did, yeah. Yeah I did. That's done.

CA: You did. So how has the AIDS epidemic changed your community or communities? Did it ultimately damage communities or make them stronger, from your perspective? Like the gay community or queer community, from your perspective did the AIDS epidemic damage it completely or make it stronger? I know—

P: Both.

CA: --in Victoria. Yeah, both, what do you mean both?

P: Uhm, I think HIV and AIDS both damaged the queer community and made it stronger, simultaneously really. The stigma was increased, and the homophobia was increased, and that was damaging. But it also strengthened. I think it brought gays and lesbians, and bi and trans, it made us more of a cohesive community in many ways, because people you know, banded together and said okay, this is our community let's support one another. So yeah for sure I see both side of the coin there.

AH: Just that, is there kind of a curve there? That things—homophobia and fear—has come back up? Like I see much more acceptance of homoph---gay and lesbian people now than there was even twenty years ago. So is there kind of a curve there, has it come back down?

P: Yeah but I don't think it was related to HIV. Like I don't the recent, more recent—well in the last decade or fifteen years or something—I don't think the fact that there are more queer rights, I don't think that's because of HIV.

AH: I've kind of connected the two in my mind.

P: Oh that's interesting. I mean I'll have to think about that, but I don't automatically think that because of HIV that society—I mean within the community, yes, we're stronger. But I don't think that stigma has decreased because of HIV. Yeah I don't, I don't think so, from my perspective. But maybe from your perspective?

AH: Yeah I had always felt that the response to it and people dying, all of a sudden oh that's my neighbour, that's my neighbour's son, and there began to be more of an acceptance of—of—homosexual people.

P: Yeah maybe I see where you're coming from. I believe there's some truth to that. But I don't think it was, I don't know I think it was other—

AH: [inaudible]

CA: Yep.

P: Yeah, yeah. I think so. But I see what you're saying. I think that stigma was—and homophobia were worse in some cases, but you're probably in some cases because it was, you know people were dying, young people were dying that you were connected to.

AH: I know when you say the, oh, Rock Hudson, big beefy, strong, handsome Rock Hudson and all those kinds of folks, it's out there in the world.

P: Although I think it would also be like, oh Rock Hudson well he's a big old fag he deserved it. Like that kind of stuff might've come out too.

AH: Yeah it could be that way too.

P: Yeah I don't think we can generalize it. But I see what you're saying.

CA: How has your perspective on HIV and prevention changed over time? So like, has the introduction of HAART and PrEP and that kind of thing, uhm, how do you feel about those? And biomedical interventions, etcetera? Have they signalled an end of AIDS?

P: Well no, just the—well I guess—no like the new medications and they're coming up with an injection to stop aids, or HIV, so you can't get it. Yeah. How do you feel about all the different, the new medical things that are happening, and Truvada as a prevention, like PrEP, like that kind of stuff. What do you think about all that?

P: Well I think it's overall—generally I think it's fantastic that there's more ways to prevent HIV. Of course. And over the years of course so many things were tried and some with more success than others. Back in the day there was this—remember microbicides? Have you heard of that? Yeah that came and went, and there was other things that came and went. And some of them were controversial, like circumcision or things like that. So those, yeah there's been always different things, uh different ways to try to prevent HIV. But of course, I mean we knew a long time ago that likely, if you're undetectable, that likely you would not be as infectious. And then the research came and has proven that, and you know it took quite awhile for that to really be proven. And then, you know I can understand when it's just, the risk is lower but it's not no risk and you know, we need lots of—it takes a long time to gather all the data from research to prove these things. So now I think that is definitely starting to change people's perceptions, and people are hopefully starting to get tested more. Although of course we still need, that needs to be promoted always. Uhm but I really loved how a few years ago that hospitals—whoever came into a hospital was getting an HIV test, and I thought that's the way to do it.

CA: You don't think that's too invasive?

P: Nope, not a bit. I mean people—as long as they're told. And they're you know, it's consensual and they're—it's being recommended but they're not—nobody's forced to get that test. Then I think that's totally the way to go, make it part of routine healthcare.

CA: I totally agree with that, I have run into people who don't. But I totally agree with that.

P: Absolutely. Just like you get screened for all sorts of stuff. You know. Yeah, screen me for diabetes screen me for cancer. You know, screening. That's how you get people diagnosed with everything.

CA: Uhm, do you have any advice for health professionals, specifically in regards to prevention and support efforts?

P: Well in terms of support—

CA: How can they be improved. What are your thoughts on that?

P: Well in terms of healthcare professionals supporting uhmm hmm—well of course not lately as much but of course I've been asked many times how did I get HIV. I was asked that by an herbalist. And I was immediately, like irked, so I said well why—why do you need to know that? And she got a bit uncomfortable and said, 'well it might affect how I treat you.' And I said, really? How so? And I you know, soon realized she was really wondering if I had ever had an addiction issue, with injection drugs. And so I said if that's what you want to ask, please just ask that. So of course having health care professionals be sensitive, and educated for sure. I still—now moving to a smaller community's been interesting for me, because I've always come from a big city where I felt like oh yeah, I'll disclose my status anywhere. No problem, no big deal. Of course I've always heard and understood that in rural areas it's more challenging. Now I have first-hand experience. So I moved here and then it's uhm, oh hmm, now okay this pharmacist who lives down the road from me my meds are arriving at the drugstore, and so she's gonna know that I'm HIV positive. And I wouldn't necessarily tell a neighbour that, right? So it's just been interesting to have that new perspective of oh, this is what's it's like for people in small towns and rural areas. You know, you don't have that confidentiality so much.

AH: Have you had any reactions?

P: No. Not at all.

AH: This is mostly within yourself?

P: Absolutely. Within myself. I know yeah.

CA: Isn't that interesting?

P: It's very interesting. And I'm someone who's been very open about my status over the years. And then—but to be faced with this, well moving into a new community people don't know me yet. I don't want the first thing that they know about me to be HIV. I don't. I want them to know [name], and other things about me. Not HIV. I don't go around talking about my health problems of course. I'm not sick. I'm well. I'm perfectly healthy, I don't feel the need to disclose my status in very many places anymore. I'd prefer not to really. Although I have no shame—at least I think I don't, really—but I still want to have some control over who knows, and how they know, and when they know. And so in a small town it's a new—a new experience for me—it's like a whole new ballgame it's like ahh, okay now I get it. So I hope you are interviewing some people from rural areas as well, not just Vancouver and Victoria. Well Salt Spring now you have. I don't know if you're interviewing Marguerite but.

CA: We have talked to people that have come from rural areas and are now living in Victoria, and their experience when they were in the middle of nowhere.

P: I think that's a very important perspective to have. And now I'm getting it on another level, so.

CA: And who would have thunk it at this point in your life, and you know this point and that being way back there and you know—

P: But it's fine really I got my—it was just a thought passing thought and feeling that came through me and then of course I'm going to disclose and not worry about it and I haven't experienced anything negative from it, at all. But still I have that little feeling of oh, do I want them to know? Or do I have to disclose here? It's a small community.

CA: I have a question. So I'll give the background to my question, so I used to go to schools and talk, all the time. And I got invited up to Gold River, very small place, to speak. To the high school and the junior high, my brother lives there, his three kids, my sister and her husband live there. And so I spoke to all of them ahead of time—like the kids and my sister and her husband and yeah, all of those people—to see how they felt about it, because they're the ones that live in that small community. And I know you've moved into your brother's community.

P: Right. Oh I haven't even asked him.

CA: Oh okay. I was just curious.

P: That's an interesting question, but nope. And I'm pretty, I'm quite confident my brother would be totally fine and totally supportive. He's my brother, he's him and I'm me, you know it doesn't—and I think because the stigma of HIV I believe has decreased, it's certainly still an issue for sure, a big serious issue. But it has decreased a lot over the years. And maybe he would've felt differently twenty years ago, I don't know but—but—you know and I didn't even think to ever check that out with him, at all. Just because I'm pretty confident of his answer. And he's not the same brother—he's not my gay brother who I worried about having HIV. So he's—yeah.

CA: Actually this island is very open, I've spoken at the elementary school I've spoken at the junior high I've spoken at the high school. It's been fun.

P: Oh really.

CA: Hello? What's happening? Is our battery running out?

P: I'm blathering on, too long.

AH: Is that our machine?

P: There's a chance it could be my phone.

CA: We only have one question left. Any advice for politicians or legislators?

P: Oh god no. Any advice for—no I could probably answer it.

AH: You could say something rude.

CA: You could say whatever you want. Others have. It's not rude it's just blunt, there's a difference.

P: So any advice—say it again?

CA: Any advice for politicians and legislators on current prevention and supportive efforts?

P: Uhm that is one—that is a bit of—okay the downside of Doctor Julio Montaner I appreciate him very, very much, he's been a big gift to our community, and he's really put it out there that HIV is basically a chronic manageable condition now. And for the most part that is true, for people who can access the meds. And a lot of people cannot access the meds, for various barriers and reasons obviously. So uhm anyway so because he's saying, 'oh HIV it's very treatable.' And he's really—yeah it's like diabetes—he's really put that message out there strongly, so the medical community and then in turn the funders and government are feeling like HIV is not a problem anymore, so we can cut services to the Positive Women's Network, and a whole bunch of organizations got their funding slashed. Some of the organizations have disappeared—like the Positive Women's Network—and that was a big loss. I mean I do agree it didn't need as much funding necessarily, or things had to change, but uhm, so now it's sort of like a new era. And also I'm seeing now Hepatitis C, it's all being grouped together which in many sense does—I can understand why, however we need to maintain services that are specific to people living with HIV. And we need to maintain what little funding we have. So yeah my message would be keep funding services. The reason we're doing so well and people are taking their meds is because we have support. If you pull away funding to these organizations, people will not have the same amount of support and might not be able to adhere to their medications as well. And then you know, I mean we have the potential to end HIV just in terms of everybody taking their meds and having what they call an undetectable—a community viral load that is undetectable. You know in the big picture. But we need to keep support, support and treatment and care all of those things need to be maintained, not decreased. It's way too soon to be pulling the plug on those kinds of supports. So, that's my feeling about that.

CA: Functional cure, it's called.

P: What do you mean functional?

CA: A functional cure.

P: Societal.

CA: No functional within your body, so the meds keep—it's a functional cure. It's still there but it's in the recesses, but as people who are positive die, then the virus dies with them, they're not passing it on to anyone else.

P: Now you're not talking about aging and HIV, are you?

CA: No.

P: You're not asking about that. Okay. That's alright because we're dishing about the past. Although I have aged now, I'm fifty-six, who would have thunk.

CA: Ah you're still young.

P: Well I started turning grey and I was—I'm like celebrating the grey hairs really. You know my friends are all like oh my god, we're getting old, and I'm like yeah oh my god I'm getting old.

CA: Didn't think this would happen, it's exciting.

P: Bonus time.

CA: Do you have any advice for future generations who have not experienced an epidemic? How have we as a community done a good job of remembering the lessons of this epidemic, and how can we do a better job of this?

P: Excellent question. Hmm. Another big question, and I'm getting tired but uhm, lessons learned. Well in the big picture like funding, we need to fund organizations and hold them accountable and make sure uhm, people are supported and uhm, I don't know maybe. I don't know, I don't feel that articulate for this one. Well it be good to have less fear, just uhm, I mean of course there's fear when it's the unknown but yeah, I don't know, that one's a bit thought-provoking, I need to ponder that one. I think you'll have to use someone else's response for that one.

CA: It's a lot, like this whole process is a lot. It gets you thinking back to things that you'd long forgotten and hoped to never think about again. And, yeah.

P: No in a way I'm glad because it I don't know, it's given me an appreciation of how far I've come and how far we as a community of people living with HIV have come and all the support we've had from uhm, all the medical professionals and other folks, community folks, like yourself that have been there on the forefront, the front lines supporting people, so I do appreciate this.

CA: Quick question, are you still involved in the HIV community?

P: Absolutely.

CA: How?

P: I'm involved in—it's interested because now it's less about treatment. The treatment information program doesn't even exist anymore, the treatments are mostly quite good for most people. People who can access it. So that's gone, for good reason. I really don't think it was needed, now we have peer navigators it's kind of taken that place which I think is a brilliant thing. Well basically with peer navigators that's been happening for years and years, and we were doing it informally already, and then it became formalized, paid positions, fantastic.

CA: And what's a peer navigator?

P: A peer navigator is someone, often connected to an organization or hospitals and clinics, where somebody newly diagnosed, or just someone who needs peer support, or connection, can go and learn to navigate the system and learn to navigate living with HIV. And it's peer-based and that has now been proven to show that it's very effective. You know if people can accept and get their head around living with HIV and the diagnosis which can still be very earth-shattering, then they're more likely to get the treatment they need and the support they need. I think. And hearing, having you know you need a whole community of people supporting you. But having a peer connection is very important. A lot of people who experience the most stigma don't want to walk into an organization that's called you know, Positive Living Society or AIDS Vancouver or AIDS Vancouver Island. They don't. There's too much stigma. They've come from countries maybe where there's still a lot of stigma, and that stigma's stayed with them. So they have self-stigma, and that's very harmful to their own acceptance and to their own ability to take care of themselves, or even just take their medication. What was the question?

CA: Do you still have a role?

P: Yeah so I'm glad that the treatment information that that's long gone, and I'm not involved with BC Persons with AIDS Society which changed to become Positive Living. Uhm, now I'm involved with the Positive Leadership Development Institute through Pacific AIDS Network, and so I think it's wonderful because what that programming aims to do is help people build skills. And get either back into the work force or volunteering, or just have some professional development. It’s an opportunity, in a room full of peers to improve yourself, build your confidence, do public speaking if you want to do that, uh learn communication skills, learn about what your values are, and just live a better life. And I think that uhm—so it’s pretty cool to see how the services have changed over the years from just helping people stay alive to now hey, uhm, your quality of life can be excellent living with HIV. So that’s pretty amazing actually. So it’s pretty god feeling to be involved with that. So I’m a trainer, I have been for ten years now actually, and we’ve run so many of these trainings around BC and we’re continuing to do that. So I’m proud of the work that I do there.

CA: Any last words?

P: No I don’t think so. I think I’ve said enough, I’m probably up there with some of your lengthier—well two hours, I’m sure you’ve had some chatty people.

CA: Chatty people are good, a lot of information comes out when you just start chatting.

P: It’s taken me awhile to get sort of warmed up a bit, because I know I was putting some people to sleep at first.

CA: I think that was halfway through.

P: Oh that was in the middle.

CA: That’s why we trade off.

P: So you’re gonna talk to the boys tomorrow?

CA: Yeah we’re going to talk to the boys tomorrow.

P: Oh I’m sure that’ll be—you better reserve several hours for that.

CA: Oh yes, we do. So thank you very much [name].