

“HIV in My Day” – Interview 22

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Interviewee: anonymous; Interviewer: Sandy Lambert (SL); also present: Ben Klassen (BK)

Interview anonymized at participant's request

Sandy Lambert: Okay, so how long have you been positive for?

Participant: It will be thirty years [in] April this year.

SL: Wow, that's a long time.

P: Yeah, it is. Over half of my life.

SL: Thinking back there, how did you find out?

P: I found out that I was six months pregnant with my youngest son and the doctor just told me, that, “You are HIV positive.” And I just was in shock and I started crying. He didn't give me any information on it or anything 'cause I guess he didn't know anything about it yet. It was the late-'80s and I didn't know anything about it either, so I was just devastated and shocked and worrying about my son. So, I left there, I went home, and I just wanted to get hit by a bus or something. I wanted to die right there, 'cause I would pass on the virus to my son but luckily, creator came along and he's fine. I had two children while I was positive. My youngest daughter will be nineteen this year. She was delivered at BC Women's Hospital. Dr. Money delivered her, Dr. Money helped me name her too. Her name is Asia – you can quote that. I have two sons and a daughter, and then just recently – well, not recently. In 1992, I was stabbed by my ex-partner and I found out that I was HIV positive then. I was in the hospital here, I was stabbed seven times by my ex-partner, then he only got two years less a day for that, attempted murder. But I made it through and then my ex-partner went to prison and he died in [city] in 1996. Quite a journey here. But now I am on medication. And I had Hep C as well, so I cleared my Hep C, I did the treatment they call - I forget the name of it... Saboni?

SL: Harvoni – close.

P: I was at Dr. Peter's 'cause I was really sick and I went there February last year and I did the Harvoni treatment and I left there at the end of June.

SL: I want to take us back to thirty years ago. How... there weren't a lot of support mechanisms or information. How did you deal with that?

P: I just kept it to myself. I didn't tell my family about it, 'cause I knew they would just throw me to the dogs or whatever you call it. They found out eventually. I think my son was a year old when my sister found out, and then she told the whole family of course, and I was devastated because nobody called me, nobody came to visit me. I was alone for the first, probably fifteen years. It was quite emotional for me too 'cause I had two children and then there was no

resources back then. I finally came to see Dr. Montaner at St. Paul's Hospital, and they put me on those horse pills. I couldn't take them. I think it was...

SL: Was it AZT back then?

P: No, it was C- ... I don't know – it was big round pills I could not take. I forget the name of them. I couldn't tolerate them, so I didn't start taking any medications for a long time till 1995. '95 is when I finally got into some medications that I can tolerate.

SL: Did your viral load start dropping?

P: I didn't even know about viral load back then, I just knew about CD4.

SL: So, that must have been really high?

P: I don't know what it was back then, 'cause I didn't know anything about HIV back then. It was just a disease that I got and how I got it I don't – well, I know how – my partner. 'Cause he was an IV drug user, which I didn't know – I didn't know that.

SL: That must have been very difficult to not have any support mechanism, no family to support you. You were spending all this time alone.

P: I just spent it all alone. I don't know how I did.

SL: Were you under the care of a doctor?

P: I was under the care of Dr. Montaner, until [name] was born in 1999, and then I went to Oak Tree clinic where Dr. [name] was my doctor until he retired, and now my doctor is Melanie Murray.

SL: How did you feel 'cause we come from – and we have talked about this before – because we come from the Sixties Scoop and the residential schools, how did you feel entering into that building St. Paul's?

P: I wasn't – I didn't go to residential school, I was one of the lucky ones I guess. My dad went to residential school, which I didn't find out until five years ago, and my mother didn't go to residential school, so I was pretty lucky that we lived in a 10-foot by 10-foot log cabin till I was seven years old. Minus 40 cold.

SL: Way up north.

P: Yes, and finally we left 'cause my mom got into a car accident. My brother was driving and she had kidney problems – she had to have kidney dialysis, we had to move to Edmonton, which was quite a shock from a little log cabin to a little two-bedroom apartment we lived in. I remember going on the bus with my dad and my mom was in the hospital and my cousin came with us. There was me, my sister [name], [name] and [name], [name] – there was six of us, was

my cousin and my dad on the bus and we thought that was just a long trip cause I think it was thirteen hours or something from...

SL: The North.

P: To the big city of Edmonton that I still hate to this day.

SL: I hear you, I can't stand it.

P: Really? That is where my mother passed away at the U of A. Yeah, as soon as I get in there, I start crying.

SL: How did you end up in Vancouver then?

P: Two of my older sisters lived there and I was thirteen when I came up here. Came by myself on the train which was quite an experience too.

SL: Did you live with your sisters?

P: I stayed with my sister [name] for a while, the second oldest, stayed with her for a while and went to school. And then I stayed with my other sister [name] cause I had to babysit her kid till her husband got home from work until I was about sixteen, and then I moved back with my sister [name] until I was seventeen. And I was going to that old King Ed College on Oak Street there – I was trying to educate myself – but, well, I did get to grade 12, but that was about it. I didn't continue any more.

SL: Back in the day, the gay movement had ACT UP and the different organizations that they were fighting for the antiretrovirals. Did you hear anything about that in the newspapers, that they were being advocates?

P: When was that?

SL: It was a good thirty years ago.

P: I don't recall any of that.

SL: So, you weren't involved with any of the community at all.

P: No, not until 1993, when they finally had a women's centre for positive women. It was down by the - what was it called? That fish place that is down the street there.

SL: Oh, okay.

P: That was quite a while ago, and then they moved down to this place here down to the Positive Living and from there they moved to Davie and Burrard.

SL: Were there a lot of women that were infected?

P: There were quite a few that I knew of, and my aunt got it in 1996.

SL: So, the rates for Indigenous women were climbing then.

P: Very, at a higher rate.

SL: Within your own community or your – the Indigenous community – did you have your own support mechanisms or was everyone together?

P: We were scattered around. Nobody had really any support system in place yet, just the Positive Women's drop-in, that was it. And then finally – where else was there? Oh, I found out about the Dr. Peter centre about eight years ago. I have been a member there for about eight years. And that's – and the Positive Outlook program, I have been a member there for about eight years as well.

SL: Really, there was no activism within our community, the Indigenous community.

P: Not that I know of. There wasn't anything for Indigenous women and at all or Indigenous anyone.

SL: There was one organization that did some activism, Healing Our Spirit. Did you ever go there?

P: Oh yes, yes I did, I went there. That's where I got my subsidy from and then it got transferred to Lumma House and – yes, you were right. And it was somewhere on Main Street for a bit, Main and 4th – went there for a bit. Elizabeth Benson was a support for me, big time.

SL: Did they do any sort of activism, advocacy for people up there? Or how did the...?

P: Mostly just around Vancouver area as far as I know. I didn't know how far they went up, but I know they went to conferences and that, but I know they had one in Prince George too. I haven't been there though.

SL: That was a fun one. Culture – have you always identified with your culture?

P: Not really, no. I didn't really know my culture and I still don't 'cause my mom and dad weren't very – we didn't live in a cultural... they weren't culturally, I guess, active.

SL: Anything that is culturally relevant, such as smudging or prayer or drumming, it is from seeing from someone else.

P: Yes, that is what I learned from someone else. My parents never did that as far as I know, yeah.

SL: Kind of lost here.

P: Can we take break please?

SL: Yeah.

[Break]

SL: You mentioned that you were involved with PWN [Positive Women's Network]. What kind of programs did they have for women?

P: They had the drop-in, they had lunch on Tuesdays, they had a food bank which I volunteered there for eight years I believe. And they did a lunch program and then they used to have sandwiches on Thursdays, but the funding got cut for that, and then they finally had to cut the hot lunch meal, so all that was left was the food bank. And then, finally, last year or the year before everybody got laid off and it was gone, just like Healing Our Spirit. Everyone disappeared with the cash, did the end run. That was quite a shock 'cause that's where I was getting my funding from but then they moved it to Lumma.

SL: Did any of these organizations back then have anything to do with cultural ceremony?

P: Not until just recently, until maybe 2005, maybe they started having a woman, an elder come in, smudge us and stuff, and pray and eat with us. And I guess they must have had a sweat up at UBC, but I was not involved with that. That was about it, that they had at PWN. Well, they had peer support and advocacy, they would give us bus tickets for appointments and stuff.

SL: You touched on advocacy. If you had a problem with the medical system or a doctor, were they there to support you?

P: Yes, they came with me to a few appointments. They had an outreach worker there, an Aboriginal outreach worker, but she got laid off before everybody else did. She was the first one to go. Stacy Niguans? So that was sad, sad to see her go. She had a vehicle and she would drive us to appointments and advocate for us.

SL: How did you find going into St. Paul's being a minority, back then – being a minority, no one else looking like you?

P: When they first diagnosed me, I was scared. I was all by myself, but I had no support. There was nothing – nothing at all that I can recall but doctors and nurses – maybe one or two.

SL: And how did they treat you being, as we call ourselves, brown-skinned, brown-faced?

P: Back then – my memory is going. I don't think they treated me badly back then, I think it was just my family, my peers.

SL: There used to be a lot of – in the mainstream, there were a lot of articles in the newspapers about ACT UP and the different organizations, and they were drawing outlines of coffins and they had the black bags. How did you react to all that?

P: Actually, I was scared to go out and be in that crowd. Someone would see me and the whole world would know, so I was scared to show up at any kind of function like that.

SL: It must have – there must have been talk at different organizations, at Healing Our Spirit or PWN. How did you talk about that amongst yourselves, about what you were going to do?

P: I can't remember. I don't remember much about that.

SL: Help me out here.

Ben Klassen: This is going to get you to rewind a bit – was there a sense of community in Vancouver when you moved here, I guess in the '70s?

P: I came in '74. I just didn't know anything about anybody here, anything back then. I just went to school and that was it.

SL: How did you – the Vancouver Native Health in the Downtown Eastside, did you get involved in that?

P: No, I was not involved with that 'cause I was out in Burnaby, by myself. But right now, I still live in Burnaby, can't get out of there. But I lived on Comox there for a while before I had to move cause of idiots, meaning my ex-boyfriends. He wouldn't leave, so I had to give my notice and make him leave.

BK: You talked about how when you were diagnosed there wasn't any information.

P: No, the doctor just told me and that was it. "You are HIV positive." I sat down and started crying hysterically, and he didn't say much – he didn't say anything.

SL: He didn't connect you to support?

P: Nothing, at all. I just left the office and didn't know what to do – wanted to get hit by a truck. I was just devastated.

SL: That was in...?

P: 1988.

SL: So, you go on for years and years. When did you start getting those supports?

P: I would say 1993, when the PWN came to light.

SL: So, they did play a large part in the women's lives.

P: Yes, they did. There is [sic] quite a few women out there that didn't know about the PWN either, especially on the Downtown Eastside.

SL: Did they provide information?

P: Yes, they provided everything – where to go for bloodwork, labs, doctors, all kinds of doctors, lawyers. And especially they – and the outreach worker used to deliver groceries to the Downtown Eastside Women's Centre for the women on the Downtown Eastside. That was cut off too, so the women had to bus over here and pick up your groceries and go back down there, which was quite a trek for them, I guess, 'cause they never leave the Downtown Eastside.

SL: That four or five block radius.

P: Yes

SL: How do you think from back then to today your health has been, or how do you look at HIV?

P: Back then, I thought I was going to die within – before I even had my child. I didn't know anything about it. And now, it's not a death sentence anymore – my CD4 count is steady and I am undetectable and I'm... I did my Harvoni treatment and it's okay for now. My health has been bad – last year I was in the hospital for five weeks 'cause I had pneumonia – got out of that.

SL: Something I didn't know about how people get pneumonia. How did you, did they tell you how you...?

P: No, I still have part of a flu bug going on but I'm just sick of dang pills. Yeah, especially antibiotics that I am becoming resistant to. I have seven already that I am allergic to.

SL: You are basically taking your HAART medication every day, you are compliant.

P: Yes.

SL: And you said your antibiotics.

P: Yes, I am becoming resistant to antibiotics and my HAART medication. I think this is the last medication I am on, this is the last medication they can put me on to. If this one becomes resistant, that's it, there's no more – no other choice for me but to not take any, I guess, which is really scary.

SL: Do you feel open to be able to talk to your doctor now?

P: Yeah.

SL: Do you talk about everything? You feel that there's no...

P: Oh yes, there is no bias, anything like that – I can talk to her about anything. I took my daughter with me the last time I went to see her. She was explained a few stuff – I had to have an angiogram a couple weeks ago and she was scared that I was going to die, 'cause her father has heart problems as well. She has to go to VGH, and that is quite scary.

SL: Have you let people know back in the north about your condition?

P: Not really. Well yeah, when I went back home to my dad's place. Oh my. God, yeah, when they found out, they just left me alone. I went to a party and I was just standing beside the fire by myself, so I called the police and the police came and took me home, took me to the hospital. That was quite the fucking experience – ohh, I want to kill someone.

SL: How long ago was that?

P: That was – I was twenty-seven or twenty-eight.

SL: So, that's all changed now.

P: Yes, 'cause that is a project I work on – it's called DRUM, and [name] is one of the communities. This was in [city], Alberta – big town. Quite – I forget the word.

SL: Racial discrimination?

P: Yes, that's it. Hypocrites, yeah.

SL: Has your experience – that sounds like an experience of stigma around HIV. Has that changed at all?

P: I'm not sure. I haven't been down there since that, just went to my dad's funeral and haven't been back home since I would say 2005.

SL: Have you felt stigma in Vancouver at all?

P: No, not really. I feel safe here.

SL: Yes, 'cause as Indigenous people who have to live with HIV, there are so many different layers of stigma and discrimination that not a lot of non-Indigenous people can understand it.

P: I think I'm just getting used to it and I don't have problems with anybody... yet. [Laughs] I can't believe I have lived this long with this disease. I'm just amazed at what I went through, I'm amazed at myself. Quite the fucking road, black road – walk the red road. Speaking of Red Road, I'm trying to get a hold of [name] and I can't seem to find her.

SL: Check out at the women's room at Positive Living.

P: So, that's my story. I don't know what else I can tell. Oh, I had my baby. When I was pregnant, I thought she would be HIV positive, but they put her on AZT for six weeks. She was on that for six weeks, she was premature too by six weeks and they gave me a C-section. I had edema – can you see me at 201 pounds? 201 pounds with her. Total bedrest for two and a half months and after I had her, I was at home for a month recovering from edema.

SL: Did you breastfeed your children at all?

P: No, I couldn't. I knew that I had better not do that.

SL: So, there was a special formula that you had to give them?

P: Yup, and she is eighteen. She graduated last year and she is doing great. She is going into early childhood education.

SL: Anything else? We want to leave lots of space for you to share anything else you think is crucial to your experience. Anything else you want to share with us or that our younger generation should know?

P: Just get tested. Get tested – don't be scared, don't be afraid to get tested, otherwise you'll never... My boyfriend, no, he got tested and he hasn't been – he wasn't taking medication, he wasn't on any kind of medication and finally I took him to St. Paul's and I saved his life. You know he was scared to go, so I went with him and he's okay, his son's okay. He found out he was HIV the day after his son was born. His son will be nineteen in May, so it's been eighteen years for him, it will be nineteen years. He was born in 1999 as well.