

“HIV in My Day” – Interview 25

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February 13, 2018

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

Interview anonymized at participant’s request

Sandy Lambert: So, when did you get involved in the gay community?

Participant: I think it was back in 1991, that’s when I came out. But I was in London, Ontario at the time and that was far away from my family, so...

SL: When you came to Vancouver, did you connect to the gay community or just the indigenous community?

P: The whole gay community, yup.

SL: You did the bar scene?

P: Oh yeah, and a whole lot of other stuff.

SL: Okay. What was it like for you as a youngster to be out and about? How did you feel being Indigenous?

P: For me it was fine, but it was being scared of getting AIDS at the time. People were talking about AIDS and that was the only thing that I was scared of at the time was AIDS. But everything else – I went out to the bars, partied, met people.

SL: Back then, did you find it more of a sense of a community – people came together a bit more?

P: I think so, yes, because there was a lot of people getting diagnosed with AIDS and a lot of them were dying, so people were getting more – keeping together and wondering about each other, watching out for each other.

SL: Personally – it’s not about me right now, but it was a more of a community back then.

P: Yeah.

SL: People looked out for each other. Do you find that... I’ve lost my train of thought. So, when it started coming up in the media as a gay plague, how did you feel? What was your reaction to that?

P: I stayed away from that mostly. I didn’t want to hear about it. I didn’t want to really talk about it actually. I was thinking like, “Why bring it out - why bring that out now you know? I’m just

1 coming out,” kinda thing. Now all this disease and it’s only gay people that are getting AIDS –
2 things like that, so...

3
4 **SL:** You basically sort of, became very reserved in your own sort of self about the awareness?

5
6 **P:** Yes, still really staying in a closet but just coming out when I see somebody that’s a friend of
7 mine that’s gay. “Hey, let’s go somewhere and talk about gay stuff, get drunk and party.”

8
9 **SL:** Was there a special spot back then where the Indigenous and Natives, where they met?

10
11 **P:** Usually at the Dufferin, that’s where I usually went when I knew I was gonna look for
12 somebody that was First Nations, that was gay and knew all the party areas that I went to. Or if I
13 wanted to find a friend, I’d go to the Dufferin and hang around for a while. “Oh, there you are. I
14 knew you would come in.”

15
16 **SL:** Always knew where to find each other. Did you have a lot of Native friends?

17
18 **P:** Yes, I did.

19
20 **SL:** So, as time went on, a lot of them got AIDS?

21
22 **P:** Well, most of them were diagnosed with HIV first, slowly developed into AIDS stages. We
23 lost a lot of nice people, good people, smart, educated. I think it’s only when they realized or
24 when they were diagnosed, a few of them anyway, they finally started coming out about being
25 gay. That’s when they really start being themselves and I found a lot of First Nations started
26 getting into art and a lot of them were so artistic. It was just amazing the artwork they do.

27
28 **SL:** In your eyes, that’s a way of healing?

29
30 **P:** Yeah.

31
32 **SL:** Did you find that the organizations were starting to develop back then?

33
34 **P:** Yeah, there was GVNCS [Greater Vancouver Native Cultural Society]. All that was there and
35 that was really good for First Nations that were gay and coming into the city. So many First
36 Nations were coming from different provinces and into Vancouver. They needed a place to go,
37 and usually at the Dufferin.

38
39 **SL:** When you were diagnosed, how did you find you were diagnosed

40
41 **P:** I was living in London, Ontario at that time. I think it – I was probably in my early-thirties
42 and I was in a treatment centre, and they asked that we go and do a blood test every three
43 months. So, I went in and they tested for HIV or AIDS at the time. The first time it came out
44 negative and I went back and I kept going back, and every three months. And then finally in
45 October that one year I went in and it came back positive, and they thought it was somebody
46 else’s blood. They thought maybe they made a mistake, so they took another blood test and it

1 came out positive. So, that's when I was diagnosed, and the doctor, he stood away from me
2 probably like ten feet. He didn't want to come near me and things like that, so I felt really
3 isolated right away. I felt really scared. But he didn't come and console me, grab my hand, and
4 say I got bad news. He just told me he's got some good news and he's got some bad news and he
5 asked me which one I wanted. And I said the bad news, and I thought it was going to be AIDS
6 and he said, I'm HIV positive. And I said, "What's that?" And he said, "It's a virus that causes
7 AIDS." And I just didn't know what to do. Then I asked him, "Well, how long do I have to
8 live?" He said, "Well, if you take good care of yourself, you might be able to live another ten
9 years," just like that. And I said, "Just ten years? That's not very long. What am I going to do in
10 ten years?" And that's all he said. He never gave me any kind of information, where to go to talk
11 to somebody or anything like that.

12
13 **SL:** Which is pretty outrageous compared to today. So, what did you do? How did you find out
14 your information?

15
16 **P:** There was really nothing back then, just a drop-in centre in London, but I didn't – people were
17 scared to go by that place because it was the first AIDS organization that opened up and people
18 didn't want to be around there. Then I start going there and it was all run by non-Native people
19 and it was pretty scary. They asked really, really awful questions about my sex life and how did I
20 get it? And what was I doing? Just like it was my fault, and I guess it was, but then you don't
21 want to think about it. I knew I was – I try to be as cautious as I could and just... I just went
22 numb for a least six months but then there was the news every – not every night, but every week
23 or something there was something about AIDS, talking about AIDS. And it was mostly in the
24 USA back then – gay plague, gay cancer, and then it started coming to Vancouver. And then gay
25 people started getting AIDS here. But then the research was here and I was in London and I
26 started hearing about research being done about HIV, so when I got my welfare cheque, I just
27 went to the bus station and bought a bus ticket with that welfare cheque, jumped on a bus, and
28 came out here.

29
30 Almost four days on a bus, not knowing what was gonna be out here, but I had a sister that lived
31 out on Salt Spring, lived on the Gulf Islands. So, I called her and told her, "I'm coming to
32 Vancouver," and she got all excited. When I got here, she met me at the bus station with a friend
33 of hers from the island, and we just went out drinking for a couple of days, even how weak and
34 tired I was. And then we went all the way to Salt Spring. But at that time I didn't know to go on
35 disability, so I stayed on Salt Spring for probably eight months and I said, "I gotta go to
36 Vancouver and start getting involved with finding a doctor." So, I did. I packed everything and I
37 moved here and the only place I could find that was cheap was in the east end, so I found a hotel
38 room that just – cockroach infested and loud music all night. People breaking into my room and
39 lose all my stuff, but was it ever rough. For probably ten months, just getting to know my way
40 around, and finally I start running into First Nations people that were HIV. You know, [name]? I
41 got friends with him and he start showing me around Native places to go and whatever and his
42 doctor was Dr. Carol Murphy at that time, and he brought me to her office and introduced me to
43 her and said here's a patient. And she took me under her wing because I really didn't know about
44 blood work back then, and CD4, and what's the other...

45
46 **SL:** Viral load?

1
2 **P:** Yeah, all that, it was all new to me. But she was good at explaining all that and then you know
3 they start talking about blood and how much blood they are gonna take, and I thought I would be
4 running out of blood, not knowing you can reproduce it. I said, “Gee, I’m gonna loose so much
5 blood by the end of this.” And they wanted me to go on AZT at that time and I was really leery
6 about that because I heard so many stories about AZT back then. People were diagnosed with
7 AIDS and they put them on AZT and it didn’t work for them. So, they were telling me, “You
8 know, [name],” the close friends of mine, “If you ever get diagnosed with HIV, don’t go on
9 AZT. It’s not gonna help you out at all, it’s just going to make you worse.” And she put me on
10 AZT and I took one and I thought, “No, I better not.” And I went back to her and I told her I
11 didn’t want to take them, and she said, “That’s okay,” because you know they are still doing
12 research on the medications and you know the better ones are coming out, so she said, “Just
13 wait.” So we waited for about six months and she finally introduced me to a cocktail. It was three
14 in the morning and three at night and I went on it for about seven years. And one of them was
15 D4T and I didn’t know that one was damaging my nerves, and I was taking that for so many
16 years. Then I switched to – went down to three pills a day. That went for about five or six years
17 and now I am on a triple – just one. And I had no idea that my nerves were damaged and you
18 know, I thought I was getting all crippled up and stuff like that. I was living in Prince George for
19 thirteen years and it was getting worse, my nerves they were getting really bad. I was shaking all
20 the time and my dad was diagnosed with Parkinson’s. “Do you mean I got Parkinson’s now?”
21 ‘Cause I couldn’t even hold a cup. And two years ago, I decided to – “I might as well come back
22 to Vancouver,” because the doctors there are not really educated that well around HIV and meds
23 and things like that, you know. So, I came back here and that’s when they found out about that,
24 my damaged nerves. So, I’m really glad I moved here.

25
26 **SL:** You talk about the healthcare management you received from doctors and nurses. How did
27 you find them in Vancouver compared to Prince George?

28
29 **P:** Oh, they were really good here, you know, they were really understanding. I couldn’t imagine
30 how the healthcare was back then with people living with AIDS, how much the people that
31 worked, the nurses must have went through back then to care for somebody that had AIDS. And
32 me, just HIV, but they treat me really well, really helpful. I go to the Dr. Peter Centre. There’s
33 lots of support there. There’s lots of information about HIV stuff.

34
35 **SL:** So, you talk about support. What kind of support mechanisms are there?

36
37 **P:** We have a nursing station to get your meds there. There’s music therapy and then you get a
38 breakfast and a lunch, seven days a week. You can go out and hang out there for the day and they
39 have outings once a week.

40
41 **SL:** Is there any type of cultural relevance because I’ve heard there used to be culturally relevant
42 programs there?

43
44 **P:** Not that I know of. I think they try to but it just goes to the wayside, because there’s not many
45 First Nations there – there’s only a handful.

46

1 **SL:** You also talk about Prince George, that the doctors were not competent. Did you find that
2 they cared enough about the patients?

3
4 **P:** Not really. You know, their attitude toward people – I know one doctor there, he’s just awful.
5 He’ll just sit there and not really do nothing. You’re talking and he’s saying, “Yup, uh-huh, uh-
6 huh, yup.” And I’m thinking it’s my health I’m concerned about, and he’s just, “Yup uh-huh.”
7 So, I didn’t complain about it but I mentioned it to one nurse and she said, “Okay, we’ll let you
8 see some other doctor then.” And so I saw her instead of him and they were saying he was a
9 specialist in HIV and I said I didn’t want to see him at all. I just saw him two or three times and I
10 said I didn’t want to see him ever again.

11
12 **SL:** Was that Dr. [name]?

13
14 **P:** Yes. Don’t tell him I said that. You are the one who said his name.

15
16 **SL:** We’ll edit that out. That’s the reason I came up to the north to talk to you guys about the
17 health care system and how you talk to doctors.

18
19 **P:** You know, the history with First Nations and authority, it’s just crazy there. It’s really, really
20 awful.

21
22 **SL:** Have you been admitted to the hospital up there or down here?

23
24 **P:** Yup, up there I was treated really awful. Just awful. There was something wrong with me, I
25 was in and out of it, and I was pressing the button. And the nurse would come into the room and
26 just start yelling at me, “You’re not my only patient, you know. I have lots of other patients.”
27 Just yelling. And that’s what really opened my eyes and I thought, I gotta talk to somebody else.
28 And I waited till he was gone and I called somebody else and I explained what happened. And I
29 said, “I wanna go now and I don’t want to be here anymore.” And they said, “No, you can’t go.”
30 I said, “I wanna go. You guys can’t keep me here.” So, they got somebody from higher up and
31 talk to me and I don’t know if they figured it out or whatever but that really scared me. That’s
32 when I was gonna leave so I thought they took care of it.

33
34 **SL:** That leads into something else – advocacy and looking after yourself. Did you ever have
35 anybody else that helped you advocate for what you needed?

36
37 **P:** No, I always used my own voice.

38
39 **SL:** Which is really important.

40
41 **P:** I think I get that from my mother.

42
43 **SL:** That’s why it’s called two-spirited. So, your experience was not very good up in Prince
44 George?

45

1 **P:** The living was okay sometimes, but it was just my health I was really concerned about and
2 just the treatment. And then it just started getting worse, where I really couldn't go out any more.
3 I just stayed at home and then I just started realizing, I think it was about after six or seven
4 months, I realized, I'm staying at home now. I didn't like that. I like to be out running around.
5 There I was just staying a home. That's one of the reasons I moved here, and my health is really
6 improved since I moved down.

7

8 **SL:** You find down here things are a lot closer here than there when it's minus 40?

9

10 **P:** Well, it's not that cold but then there's the two rivers that meet there and when it gets cold in
11 winter, like it's minus 30. I've been watching the weather and there's a lot of snow. Minus 30
12 and positive, living north, they couldn't even be open because they live out on reserve, most of
13 the employees, so they didn't want to be out on the roads, so they didn't bother being open. I
14 don't know where the participants went. There was a lot of concern about the participants, where
15 they go.

16

17 **SL:** Was the fire pit open?

18

19 **P:** No.

20

21 **SL:** No fire pit wasn't open either.

22

23 **P:** No.

24

25 **SL:** So, there was no support mechanism, there was no meeting places, so weather does have a
26 lot of factor.

27

28 **P:** Where here we get rain and we get fog. "Oh, I can't see."

29

30 **SL:** Did you ever – I know in the Indigenous world we lost a lot of people who started up the
31 movements from HOS [Healing Our Spirit] – I won't say the full name. We've had people from
32 Red Road, and you know the two gentlemen I refer to.

33

34 **P:** Yup.

35

36 **SL:** So, you were part of that?

37

38 **P:** Mostly with Healing Our Spirit. We went for conferences and to different parts of BC which
39 was nice. Conferences were good because there was information about First Nations
40 communities, how they were dealing with HIV, or if they were dealing with it at all. Or how can
41 they get access to HIV meds on reserve? How can they find support when they were diagnosed?
42 Because back then it wasn't really talked about on reserve. I know one chief, I was gonna talk to
43 her about HIV just in general, and she said, "Oh no, we don't get that on our reserve." And I
44 said, "You just don't know. It could be your own nephew." Even how much you believe in God,
45 it's still there. Somebody is HIV positive. Maybe they are and they just aren't saying anything –
46 they are just too scared.

1
2 **SL:** So, lots of change since the '80s, when the epidemic started, to now. Have we progressed a
3 lot? Maybe we are in a better place? How do think the next generation – how do you thing they
4 are going to deal...?

5
6 **P:** Well, I think if you live in the city, you will be fine, but once you are gone to the small
7 communities it's really hard, because people just don't know enough about HIV and how they
8 can get it, and they still think you know it's a gay disease on reserve, you know. It's – they just
9 don't talk about it a lot.

10
11 **SL:** How do you think that could be changed because it still is a bit of a dilemma. What do you
12 think needs to be done?

13
14 **P:** Probably in the schools I think. I remember going to Stony Creek for a meeting there and this
15 one woman, she had no idea that there was a women's condom, and I never seen a First Nations
16 woman so happy. She – I was just on that little reserve for a couple days and she was, "Yay, we
17 got women's condoms." Just something like that, just go teach people, and say hey, there are
18 ways you can prevent it. And there's medication now, instead of being so scared about HIV and
19 who gets it or whatever.

20
21 **SL:** In our culture, for years and years we weren't allowed to talk about sex. It was taboo. You
22 just do it, you don't talk about it.

23
24 **P:** Yeah, because of religion, the residential school, and I find that so devastating because so
25 many young people today are having children and they're not educated around sex and how to
26 prevent being pregnant. And then they don't want to give up that kid, they want to keep it and
27 they don't go back to school, and then just have some more kids. And the more kids you get, the
28 bigger cheque you get, you know, that kind of mentality. And it seems like that's the only kinda
29 way of living. They know how to do it and that's the sad part. I think they should be more
30 educated around sex and sexuality and things like that and schools – most schools, instead of
31 being – not saying anything about it.

32
33 **SL:** You believe that more education needs to be done. We haven't done enough in our
34 communities.

35
36 **P:** No.

37
38 **SL:** We've done lots in the urban communities, but we haven't done much in the rural
39 communities or the really remote communities. How would you because we don't have a lot of
40 organizations with lots of money? How do we move on to progress with that?

41
42 **P:** Send a different minister in. I shouldn't say I don't know – I know. It's just being more open
43 about it and you know if you know your children are gay or lesbian, support them in any way. I
44 know my parents did and if they didn't I don't think I would be here. 'Cause I come from a small
45 community and when they found out I was gay it was uncomfortable for a day. I think it depends
46 on your parents. If your parents are supportive, it's okay.

1
2 **SL:** But that's part of our history as well, to be two-spirited. We were leaders, we were up front,
3 but it wasn't until the '90s that we brought that terminology back. You knew people that have
4 passed away. Did you ever visit the old wing or was 10C available? Do you remember St. Paul's,
5 the fourth floor? Did you visit the old wing?

6
7 **P:** The only time I went there was if I knew somebody was there and I never went there if I
8 didn't know anybody. Just somebody went in for a couple of days, that's about it. I didn't see
9 anybody else, I didn't hang out with nobody, 'cause they keep it isolated the best they could.

10
11 **SL:** Did you ever end up in "emerg" [the E.R.] in St. Paul's?

12
13 **P:** No.

14
15 **Ben Klassen:** Maybe I will jump in with a question. Where were you finding support, thinking
16 back to the mid-'90s in Vancouver?

17
18 **P:** When I first came here, there was really nowhere to go for me 'cause I didn't know where to
19 go. I just went to the Downtown Eastside, hung out there, kept my ears open, talked to First
20 Nations people, then started finding out about Healing Our Spirit. They would say, "Didn't you
21 hear about Healing Our Spirit?" No, I didn't hear about it. I got the address off them and go
22 there. That's where I started getting, started hanging around people who were First Nations, who
23 were HIV, that were living with HIV, and there were quite a few of us.

24
25 **SL:** Yes, it was like family. What about POP [Positive Outreach Program]?

26
27 **P:** I don't even know what that is.

28
29 **SL:** Positive Outreach Program at Vancouver Native Health.

30
31 **P:** No.

32
33 **BK:** And what kind of programs did Healing Our Spirit have in terms of support?

34
35 **P:** They were really more information for doctors that were taking patients that were HV positive
36 and really just a place to hang out and a lot of – they had a few counsellors there if you wanted
37 someone to talk to. They had a lunch program and then they had a few arts classes – I think it
38 was once a week or something. They bring in somebody to do art blankets or vests, to try to get
39 us back into our culture, back in touch with our culture. But there they didn't know that we were
40 so diverse – they do a lot of west coast art, crafts there.

41
42 **BK:** When you were in the Downtown Eastside, what did the community look like there?

43
44 **P:** Not very healthy. A lot of First Nations I seen living on the street. I never knew that happened
45 till I went there and started seeing a lot of First Nations on the street and I was thinking, "Where
46 do these people come from?" I had no idea and that's what really got me curious. Where did

1 these people come from? And there was very little support there, just word of mouth basically
2 down there, back then anyway.

3
4 **SL:** It's still like that, the moccasin telegraph.

5
6 **P:** Yeah, I had to go and look for my cousin a few weeks ago. I don't go there now, but I went to
7 look for my cousin. He wasn't there but I ran into someone who knew him and said he doesn't
8 really hang out there. I said, "Can I just leave?" I wasn't even there half an hour and I got that
9 information, and I said see you later.

10
11 **SL:** And you didn't get involved in the other HIV based organizations?

12
13 **P:** No, just at the Dr. Peter Centre. There was no other First Nations organizations. I never knew
14 of any other, anyway, but Healing Our Spirit was kind of a big organization back then because of
15 our travelling and things like that. Different cities, different parties, different orgies.

16
17 **SL:** Sounds like there was an element of activism involved, a lot of educating health care
18 professionals.

19
20 **P:** Yeah, we had everything there. Elders – yeah, it was quite a few workshops they used to have
21 at Healing Our Spirit, but I barely went to any of them. I didn't because I knew most of them
22 already, so I just went for the party.

23
24 **BK:** Did you find the gay community inclusive in terms of being an Indigenous guy? Was that
25 ever an issue in Vancouver in the '90s?

26
27 **P:** No, I just went out and had fun and if I ran into First Nations – I always did, we just had a
28 ball, that's about it. And back then, we didn't know when – if we were gonna, you know, get sick
29 the next day and end up in the hospital. We didn't really bother back then, we just went out and
30 had a good time. That was the kinda attitude that, once you're diagnosed, "Yahoo, let's go. I
31 don't have long to have fun."

32
33 **SL:** Makes a lot of sense to me. Anything else you can think of?

34
35 **BK:** Is there any parts of your story you wanted to share with us that we haven't asked about or
36 anything you thought we would ask?

37
38 **P:** I think mostly you're on meds, maybe ask a little about medication because you know it's
39 changed since AZT. How much it's changed all through the years, for me anyway, going from
40 six pills a day to one pill and my health has really improved since that. Some people haven't –
41 doesn't work for them, that one pill, Atripla, and I think some of them are still on the other ones.
42 I don't know what they are called.

43
44 **SL:** The combo. Do you find that – so, with the meds, do you find you were losing a lot of your
45 nerve damage, because I have heard this, but I want to hear this from you, that our Indigenous
46 have more side effects...

1
2 **P:** I don't know about more but I know that similarities are there. You know, when you first start
3 your meds, you get night sweats and what they called vivid dreams for so long and they subside
4 after. But I know with Atripla, all that went away not too long, like a couple weeks – no
5 sweating, night sweats. You know, when you are HIV, night sweats, your bed is wet, you have to
6 change your sheets, but with these new meds you're fine. It's really, really improved. I
7 remember one person was taking thirty pills in the morning and thirty pills at night, you know
8 back then, and now it's so different.

9
10 **SL:** Anything else you wanted to share with us?

11
12 **P:** No.

13
14 **SL:** Well, thank you so much.