

## HIV in My Day – Interview 23

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

Interview anonymized at participant's request

**Sandy Lambert:** So, you were diagnosed in '94 or '96?

**Participant:** Yeah, '95 – probably '94. But I didn't get into the acceptance and admitting until '96, 'cause I went into a depression – I went into just totally... I left my partner and just went kind of crazy, you know? I was living in a hotel room downtown and I just locked the world out, got drunk and as high as possible for a couple years before I came around. I was first diagnosed over there, and it was rough.

**SL:** At St. Paul's?

**P:** St. Paul's, yep. It was rough. It was – it was still kind of a – I hate to say this – a gay disease and I was a woman. I went in there with pneumonia and I was in emergency. It was awful. I was treated awful. It was bad because I guess those emergency staff were just coming to grips with the HIV epidemic. You know, it was – you know, a lot of them weren't educated, so it wasn't good.

**SL:** So, you think there was a lot of stigma between...?

**P:** Yeah, a lot of stigma, and I was Native. I was Native. And it was bad – it was bad. It's still – once in a while, I walk by there and I still – I get that feeling in the stomach – you know, what I felt like when... And I ran away. I didn't stick around in there – I just – I went back down to Main and Hastings. I guess, you'd say – like, I got it from my partner, my old man. I guess we were into the drugs and we were fixing, so that's probably more than likely where I got HIV. And where that came from – it was a crazy world, and it's still a crazy world over there. So, it was hard, it was hard, it was hard. And like I said, I went into denial for two years. Finally, in '96, I started – started realizing – like, I was starting to get sick and my immune system was just going haywire, and I went and found a doctor down there and she's been my doctor since. You know, she kind of – I guess she knew a little bit. You know, it was kind of a hit and miss thing with doctors, 'cause I had two doctors – two female doctors – and I think in the beginning they kind of used us as guinea pigs to figure out how they could handle the HIV. You know, it was sickening. You know, like, I think back now with what I know and I get angry – yeah, I get pissed off at her. I still – it took a long while to work that out. I realized that, I guess, it was kind of blaming thing and not accepting for me – for accepting. It was weird. It was, like – I was like walking in a – I can't describe it. It was like walking in a fog, not knowing, and just – you know, we were just...

I guess, not accepting it and then having to go tell my children. That was hard. That was really, really hard. And everything was falling. I was getting sick. Everything was just tumbling out of control. And I told my children and that was hard. It took a long time for me to tell them. My two

oldest children were scared – they were scared shitless because people were dying – you know, from what they heard, people were dying and they didn’t want me to die. My younger ones didn’t understand – my younger two boys didn’t exactly understand what was going on. But the two older ones thought it was – that’s it. And I still went out and messed around and stayed alone. I felt so isolated, so afraid of forming a relationship with anybody, even with my children. I was so, so afraid of forming this – any kind of relationship with anybody. It was just so – the isolation and the guilt and the shame... And the stigma – I was worried about my family in Saskatchewan, telling them. But it was funny, the family wasn’t – I didn’t tell them for a long time, but they weren’t too – they were pretty good about it, yeah. My kids came around and then I heard about the first pills that were coming out and making people sick and I didn’t want to have anything to do with that. I didn’t want to have anything to do with HIV. You know, I probably didn’t go on meds till... Jesus, 19- - the 80s? I must have been without meds for ten to twelve years before – no, what the heck am I talking about? Yeah, about ten years before, and then they were coming out with meds that weren’t so bad, but it was living with HIV... And my immune system didn’t go too haywire and...

It was weird but meeting other people though when you finally went to these – like, Native Health – like, finding other people that had HIV, it wasn’t so bad but still you didn’t do a lot of trusting. You know, you didn’t trust a lot. It was scary. You know, it was – shit. Yeah, it was scary and I still dream about – sometimes have nightmares about that. And then dealing with my children – I guess forgiving myself was – was the hardest thing to deal with, was forgiveness. Yeah. I didn’t care where I got the HIV from, it was me that was living with it – you know, it was me to blame, ultimately. And it was forgiving myself, you know. So, I stayed high and drunk for a very long time out there, you know. And then now I’m just finally just coming to grips and forgiving myself – and then the shame – and then learning about how HIV... And then it was coming out in the open – like, a whole heck of a lot more people were finding out that – and there was a lot of... And it seems like people – like the activism and activists and stuff, you know, that were... I was – I don’t know if I could... The acceptance and the forgiveness, it was like – I don’t know how to get into all this stuff. I really don’t. It’s hard.

**SL:** So, you talked about the activists and the advocacy that was done way back then. Did you get involved in activism?

**P:** No, I didn’t. A little bit but there wasn’t much. I remember Native Health was the first place I went, and it was just like a little soup kitchen and I wasn’t quite sure what it was there for, you know? But I knew something to do with HIV. There were only a couple nurses and eventually it took off – off the ground. I guess it was – maybe I got into a little bit, but it was just one big blur, you know? It was just something I hid. I hid away. I just – I hid away – it was rough, really rough. And now it’s a little different with getting involved. I’m just older and wiser – you get involved and you talk to people, you help people. You help people, you know – I guess telling them where to go, taking them to where they can get help. And like, I have a hard time opening up – like, I do. Like, I always have because I grew up in the residential – I’m a residential school survivor. So, that’s... All that combined is just a big ugly ball – a ball of...

**SL:** So, if you look at that building over there [St. Paul’s], what does that remind you of?

**P:** St. Paul's? Sometimes it – it depends. Sometimes, like, I get that feeling and I don't like it – I don't like it. I didn't like it in the beginning and I had family – I had friends that died in that hospital having HIV, full-blown AIDS. I was angry at it for a very long time – very, very long time. And now I realize that they opened up the 10-C and they're helping people. It's still a little rough in that emergency for people, and it's not only people that have HIV, it's anybody that comes from the Downtown Eastside. You know, whether they have mental illness, drug issues, they still treat you like shit in that emergency. You know, getting involved and opening up to people was a little weird. My friends I've got – like, I finally let a few people into my life and I told them. Like, I was – and they were okay – they were okay. There was not very many people that – they didn't have that hatred down there that gave me a hard time. I was surprised that a few people that had HIV gave me a hard time, and it wasn't because I wasn't getting involved or I wasn't doing anything. They were hiding behind their own bullshit, you know. And they were still blaming – you know, they were still, like – they were still hiding behind their own stuff.

**SL:** How did you know this was a gay disease?

**P:** It was, like, all over the media. It was in the media. You know, that's how we found out. And I remember when it first hit the news. I remember the first person that had HIV was a male stewardess. And I was – I must have been eighteen, seventeen. It was on the news. It was, you know... And it was, "Where did it come from," you know. And then it was just put out there as a gay disease, which was totally fucking wrong. And like, I wasn't mad at the gay people, I was pissed off at myself, you know. I didn't understand, you know, a whole heck of a lot of stuff. And I hid a lot – I just buried it – I buried everything. But finding help and finding people to talk to was the hardest – well, it wasn't the people, it was me not opening up because I didn't trust. Finding out over there that I had HIV and the way I was treated and the mistrust that I had for – it took years to get over that, a lot of years – like, a lot of years. It's just, my mind just reals sometimes. And there were times when I just blocked it out – like, I still do that. It's kind of a learnt something – you know, it's protective. I protect myself. And I guess I did get into a few things, because I've been to a few conferences, like Kamloops, learning things. I got mixed up with Healing Our Spirit and then with women – you know, helping other women.

**SL:** Did you get involved with PWN [Positive Women's Network] at all?

**P:** PW-? Yeah. That was another one. And that was kind of a bummer when they were there and they didn't tell you they were shutting down, and then all of a sudden they're gone. But then I find that with a lot of people, a lot of these places – like, they switched the Downtown Eastside, the people there. And then also, they'll come out with these rules and they'll change things. And then you have problems with the doctors down there. You know, if you're sick – and if you have HIV or if you come from the Downtown Eastside, dealing with doctors, getting any kind of pain meds, especially if you're a known addict and having HIV – it's just like a double-whammy. And it's still a problem – you know, it's still out there. It's weird but it's out there, you know? But there's such a – I don't know. It's just people treated like shit.

**SL:** So, Vancouver Native Health is – was it your biggest support mechanism over the years?

**P:** Back then, yeah. I guess that's been my biggest support and then coming to PWN, and then Dr. Peter is a good support, you know? But then it's up to me if I reach out – but then I still have a problem reaching out, you know, because there's such – it's just weird.

**SL:** How did you end up with Dr. Murray, your doctor now? How did that work?

**P:** That was – I needed to get away from the Downtown Eastside. I needed to leave there, you know? It was – I moved to this end of town, I guess nine years ago, and then I kept seeing the doctor down there – down at Native Health. But it was getting to a point where I didn't want to go down there anymore. It was just me. I was getting older, you know, and I knew that – and then I'd kind of feel shitty about that because I knew that's where people needed help the most if I were to get involved, but I wasn't ready to get involved. I was just hanging on because I was trying to come out of an addiction – and I've been straightened out here since I moved over here.

**SL:** So, you had to get out of the Downtown Eastside because it wasn't a very good place...

**P:** And I moved over here – it's now nine-and-a-half years. And I stayed down there – I kept a doctor down there until – I guess I just switched over in the past eight months. It was just – it was getting too much for – because I'm older and just getting on that bus, and... I don't know what was going on. I had to just change – change the scenery, even though it's further over that way. And it gets me out of myself getting on that SkyTrain instead of getting on the bus going that way.

**SL:** So, is Oak Tree your only support or...?

**P:** I still – like, if I have an emergency or something or I have to see a doctor – like, I went to Native Health today because I have a bit of an ear infection. Instead of going all the way to Oak Tree, making an appointment, I went down there – there was no way I was going to go over [to St. Paul's]. I avoid that place as much as I can now, although there are people I know that are treated okay – it's half-assed though.

**SL:** I'm lost for words.

**BK:** How long have you been in Vancouver for?

**P:** I've been in Vancouver since, I guess, 1979 if I wrote that properly. See, it's hard for me sometimes to put dates to things because, you know, sometimes it's totally opposite, you know?

**SL:** It's a long time ago. [laughs]

**P:** It was a long time ago, yeah.

**SL:** So, you left Saskatchewan? You're from Saskatchewan?

**P:** Yeah, I left Saskatchewan, I'm from southern Saskatchewan – sorry, south-eastern Saskatchewan.

**SL:** And then how did you get here?

**P:** I got here with my kids' dad. He came out here to work and it didn't work out, and we split up. He took the kids and I went off and wrecked my life, pretty well much. Yeah. You know, I'm honest about it. I have to be. But you know – like, I'm happy that ARVs came out because – I'm really thankful that my kids didn't have to go through that – like, dying of full-blown [AIDS]. When I first got HIV – this is sick – I would rather have ODED than died of AIDS. You know, that was my way of thinking – it was my way of thinking – “I'd rather OD than die of the full-blown AIDS.” Which is – you know. And now I just – I'm okay. I'm okay with where I'm at in my life. My kids are okay with it, you know. I take my ARVs. I like where I'm living.

**SL:** So, it's different than what it was back then. It's a better life for you.

**P:** Oh yeah, it's a better life, you know. And another thing – like, living in a hotel room and having HIV was the shits, you know. And I didn't – they care about health – that just didn't... It was really hard to look after your health, you know, living in the Downtown Eastside and living in a hotel room. And then moving up here, having a decent place to live, kind of – it changed things. It changes your whole perspective of, you know, wanting to stay alive or wanting to live, you know? Just having that decent roof over your head. It was scary in the beginning – like, am I going to make it? Am I going to make it or am I going to go back down there? Am I going back down to Hastings? And it didn't happen. But it was hard. It was a real hard thing to do.

**SL:** So, it's kind of nice to hear because I also work in downtown on one of my projects – that people don't want to go back there, right? They're out here, they're in the West End, and this is where they're happy. You've got the hospital, you've got Oak Tree. They've got everything they need here. So, that's great, that's wonderful that you can learn to survive again – live, I guess.

**P:** Living, yes.

**SL:** I guess you feel you're in a better place than you were back then?

**P:** Oh yeah. Way, way better. There's happy – there's peace in my life. You know, it's like way better. Like, it was totally insane before I came to – moved over here nine-and-a-half years ago.

**SL:** How do you educate yourself on HIV because it's been – from where it was in 1980 to where it is now, things have changed. How did you educate yourself?

**P:** You know – unbelievable. Native Health there – a lot there. And then Healing Our Spirit helped a lot. And then that one went kind of weird and wonky too. [laughs]

**SL:** I know. [laughs]

**P:** And then PWN, and then Dr. Peter. And like, people – people with HIV will give other people information, you know, which is really helpful. Like, I've got a good network of people that I can talk to. And it took a long time to trust, and they get that. And then having my kids sort of

involved. You know, like, they're involved – they're interested in my health, the meds I'm on, the whole thing. Just in case something goes crazy with my system, they need the information so that if I have to go to the hospital...

**SL:** So, they can be your advocate, they can be your other voice, which I tell people as well, because it's the world I work in. It's always nice to have another set of ears, another voice, because there's going to be place one day when you can't use your voice.

**P:** You know, getting set up for when – like, I'm not going to always be here and getting it down on paper, and setting it up with Dr. Peter and Native Health. And Dr. Peter, I'm surprised, they don't have a person you can go to and get this all down on paper – they don't have that there. Like, I asked about it the other day – I was quite surprised. But Native Health has it, but I gave Dr. Peter a copy to put in my files because I thought they would be helping people. And then I had to give it to St. Paul's because I ended up there a year ago with pneumonia, and so I had to give them...

**SL:** A living will or whatever?

**P:** It's now called a living will. I had to give it to them. As for the hospital, like, I've come to realize that the wards – once you get past emergency, you get to the wards – they're okay. But it's getting past the goon squad in – what do you call them? – in emergency that's the worst part of going there.

**SL:** Do you feel there's a lot of stigma in emergency because of "brown face?"

**P:** Yeah, that, and people that come from the Downtown Eastside that have mental issues and HIV. Like, they're not supposed to be like that but it's there, and they have the goon squad there that hurt a lot of people and throw a lot of people out of there that need help. It's security that I'm talking about.

**BK:** All these layers of stigma, right?

**P:** Yeah.

**SL:** Yeah, being Indigenous, being HIV, and from this area...

**P:** It's like climbing up a ladder. But it's got to the point where I'm over it now. Some of it bugs me. If I see it happening to somebody else – I can usually walk away from it, like, "Screw yourself." But when I see it happening, especially to young people from – you know, young kids from downtown over there – like, I see it happening to them and it kind of bothers me. I remember being there. I remember totally being there and knowing how they feel. It still brings a little – it brings something back in my gut. I feel it in my gut.

**SL:** Do you feel over the years you've learned how to maneuver through the healthcare system?

**P:** Yeah. You know, sometimes it's easy, sometimes it's not so easy. Like, at one point I was on these ARVs and my doctor gave me this one ARV and it shut my kidneys down. And I thought, "There she goes. She's treating me as guinea pig again," you know? And then it's really funny, when they came out with different pills and stuff, they use them on the people in the Downtown Eastside, like they tried it with me. Like, these anti-depressants: "Oh, you can take this. It will put you to sleep." It just made more buggy. It didn't help at all, you know?

**SL:** Is there anything in the earlier days that you want to explain a little bit more or that you haven't told us? Let me just ask this question: do you think that community – I'm talking about Indigenous communities – do you think they came together a little bit more, or was everybody still in their own little...

**P:** Maybe in the cities they came together, but on the – like, on the reserves and stuff, like there's – there's still a lot of ignorance. There's no support, you know, for people, especially in the Northern communities where the epidemic has just gone crazy. Like, in Saskatchewan, it's just gone nuts – you know, in Northern Saskatchewan.

**SL:** Yeah, I know. It's amazing that that's still there, you know, after what we went through in B.C. and the rest of Canada. Our Northern communities, Indigenous communities, are still so ass-backwards.

**P:** Yeah. Like, it was funny – about two years ago, they came – they got us to come and talk – people came from Northern B.C. and it was workers – you know, the health professional workers and they came and asked us what we thought Northern B.C. wanted. And I was kind of like, "Why don't you go and ask them? They're the ones that live up there." You know, and I told them that: "You're asking the wrong people. You should be asking the people there what they need." You know, like, it was – I couldn't get over it, you know?

**SL:** Yeah, go to the community that you need to help. Don't come to us.

**P:** Yeah, because we've been through that. We thought that's already been fixed. You know, and it's so different over there – we don't know. Like, I can't imagine going to my community – I just can't see it anymore in Saskatchewan. I just can't see it happening. You know, with the HIV and... You know, I don't know what – I know my family in Saskatchewan was okay, but I don't know about the rest of the reserve. I don't know how they'd take it, you know, because I've known, or I've heard the next reserve over from where I'm from, this person died of full-blown AIDS and went back – they took the body back, and they were scared to open the coffin, the casket, you know? And I don't know if it's still happening back there. It probably is.

**SL:** I've heard stories.

**P:** Yeah, it probably is. You know, there's so much that the reserves, the communities have to be taught. You know, it's like anything else.

**SL:** Who do you think is responsible for the communities, to educate them?

**P:** I think – to a certain extent, I think it's us. I think it's us. Like, I think it's time for us to step up – like, the old-timers that have HIV – step up. Step up and – but then it's reaching some of the people. Some of them just have that barrier up. On the reserves, they just don't want to hear about the truths. It's not as bad as – you're not going to get it if you open up the coffin of someone who's dead. You know, some of them have just got – and I find there's a lot of discrimination amongst people on the reserves, especially if you've left the reserve and you go back – you know, and you've got HIV, and they're not going to listen to you. You know, there's that discrimination – like, I don't know what it is. I can't figure it out.

**SL:** It's like people who leave the reserve to get educated and then they come back three years later: "Oh, that person..."

**P:** Exactly. Which is crazy.

**SL:** It is. Any questions?

**BK:** I'm curious about – you left the Downtown Eastside, which is a community. Where's your community now? What does it look like now?

**P:** What does my community look like? My community is this part of town, you know?

**BK:** The people in your life, I guess.

**P:** The people in my life are the people in my building because I do hangout with people who don't have HIV. And then there's the people – my HIV family, you know? That's it, you know? There is the gay community – it's all just part of it. There's a lot of kids that live in the community – there's parks. It's like totally different from coming from there, and I was homeless when I came from there – I was. And I went to see – I ran into this one worker and she helped me so much to get out of there. I was totally homeless, living on the streets. And I was – and I just turned fifty, so it was time to – you know, time to get out of there. I was going to die down there. And I got over here and I started taking my meds, and I started opening up to interesting people. It was long haul that – you know, this last nine years – you know, getting this far.

**SL:** Do you think that this community has the help that you require in order to keep going if you ask for it?

**P:** That – yeah, that – and... You go down there, you see what's going on, like every few blocks. Like, here you can walk down the street. You can walk for blocks and blocks and no one comes and gets in your face: "You want drugs?" You know, and it's not – you don't see that damage and stuff over here that you see down there, even though sometimes I have to go down there. It just – I still get a knot in my stomach on the bus going through down there, and then I see the devastation. I see the kids – I see the young kids – white, Native, it doesn't matter – it just puts a knot in my stomach. It just hurts a hell of a lot, seeing that.

**SL:** As we said before, you're very resilient. I think most Indigenous – well, women are very resilient. Men are resilient too, but...



**P:** Like, we were talking the other – these young kids – young Native kids – how kids have HIV. It's time to talk to them and get them involved, you know? It is because they're the next generation that's gonna...

**SL:** But how do you do that? Like, I've been trying to work on that for years, so...

**P:** I know, because it's so hard. It's so hard, especially down there. You could be – you know, you go to sit and talk to somebody, and it's just like – you know, I know it's frustrating. I know it is. I guess it's getting them out of their drug-induced – like, when I had to get out of that drug-induced haze – get them decent housing, you know. But then you have to be willing to do that, you know. And that's what it was for me is that I was willing to make that change. It was either that or dying, and I couldn't do that to my kids – I couldn't do that to myself. It was just enough. And I was homeless.

**SL:** So, when you came here in '79, you basically lived in the Downtown Eastside?

**P:** No. [laughs] We didn't live – we lived in Surrey. It was fine. This is the Surrey before Surrey was all messed up. We raised our kids and then I had two more. Then the family broke up and he took the kids, and I went on my merry way and came down to the Downtown Eastside. And then I got HIV and it just snowballed from there, you know, until here. It wasn't good. It wasn't a pretty trip. Yeah, it was damn scary.

**SL:** But you managed to survive and you're going to live many, many, many more years.

**P:** I hope. That's it. You know, I want to see my grandchildren grow.

**SL:** Are there any changes that you need that you see that need to happen?

**P:** Yeah, there are. There are a few changes, but it's way – like, how do you deal with the Downtown Eastside, because that's the main...? Like, most of it's better over here. We know what it was like, because most of us came from down there. And it's – I guess it's dealing with them – you know, dealing with those people – and they are people. And the young ones, it's just – how do you deal with the drug system – these illegal drugs? Yeah, and then with caregivers and the government, you know – like, right now, there's a lot of... Like, they'll come in and start something up and they'll switch it when – I think they play games. Coastal Health has a tendency to play games with people, you know, and if they could just stick to one single path instead of...

**BK:** It's an amazing story of resilience and I just want to thank you for sharing your experiences.

**P:** You're welcome. And I don't know what more I can add. My head is just...

**SL:** It's all good. We need to have this history so that we can pass it on to other generations. I even have a story I haven't even told the researchers and I work on the research team. Okay. Thank you.

[End of interview, 39:17]