

**“HIV in My Day” – Interview 75**

**March 25, 2019**

**Interviewee: anonymous (P); Interviewer: Ben Klassen (BK)**

Interview anonymized at participant's request

**Ben Klassen:** Thanks so much for being here and agreeing to share your story with us. We're really looking forward to hearing about your experiences. Just to get started, can you tell me a little bit about your connection to Vancouver?

**Participant:** Well, I grew up here. This is my hometown. I grew up here in Vancouver, one of four generations born here, so yeah. Grew up in East Van.

**BK:** It's quite unusual actually to be born and raised here.

**P:** Yep. I just love it here. I go anywhere else and I always want to come back.

**BK:** And you said you grew up in East Van? What did that community look like back in the '80s?

**P:** Um, not too much different than it looks now where I'm from, the area that I come from. There's a few new buildings and old buildings got torn down on [name] St., but yeah, it's pretty much the same as it used to be.

**BK:** That's a nice area. And do you remember when you first heard about HIV?

**P:** I guess the mid '80s I started hearing about it, when I was what, fifteen years old, I guess, I started hearing about it.

**BK:** Where was that information coming from at the time?

**P:** All over TV, and I was spending a lot of time down here in the West End, so I heard about it from everywhere, everywhere you went, that's all you heard about.

**BK:** Do you remember how that information made you feel when you were first hearing about it?

**P:** Well, I was on the street, I was in group homes as a young person, and I was on the street when I was fifteen years old, so I was hearing a lot about it. And I was sex trade worker, so I heard a lot about it, and my sister was also a sex trade worker, and she always taught me to wear condoms and do all that stuff. Yeah, so that's – it was all over the place back then.

**BK:** So, it was something that you were talking about with your friends?

**P:** Yeah, it was. At first, for a lot of people, it was kind of a joke, right? And everyone was like, it's a gay disease, it's a gay disease, right? So, everyone was like you're okay if you're not gay.

**BK:** So, there was a bit of a sense that this doesn't relate to me and my life.

**P:** A little bit, but I was still very cautious and very safe. Even though I was doing what I was doing, I was very careful about it. And I thought I knew who I was around for the most part, but there were a lot of people who were HIV and had AIDS and were dying, but they'd say they had, like, cancer or something like that. It sort of looked the same – you didn't know what it sounded like, acted like, looked like – kind of had an idea what it looked like, but people could say they had something else, and you might let it pass.

**BK:** Were people starting to get HIV around you?

**P:** Yeah, actually, a girlfriend of mine – well, not a really a girlfriend, but somebody who knew me, and she would have already been on the street for a couple of years. And there was a lot of it – like, you could see people who had it, but you weren't sure, because you weren't sure what it looked like at that time. This girlfriend came up to me and she says, "Oh, this person that you're with," this fellow that I had just started dating, had given her HIV. She just got tested, so she told me to go get tested. And I had used a condom with this person, and it broke. I was young and I had not developed a lot in the genital area, and inside where I wasn't producing lubricant as much as an adult woman would be, so when I didn't have lubricant, the condom broke. So, I only slept with this person once, and I ended up with HIV. So, I went and got tested right away. Actually, I was sixteen years old – sorry, I have to correct that. I was sixteen years old when I seroconverted, seventeen years old when I was diagnosed.

**BK:** Wow.

**P:** Pretty tragic, hey? [Laughs]

**BK:** It must have been so traumatic for you.

**P:** Yeah, it was. It was. You know, I knew when I needed to go in and get tested that I was going to be positive. I just knew it. This person said he had cancer, he ended up in the hospital. I visited him in the hospital, it was about six months after, and I told him, I said, "You better tell me. I want to know. Did you have it and not tell me?" And he said, "Yeah, I did." Because I forced him to say it, because I was like I'm not going to be visiting you or seeing you anymore or being here for you if you don't tell me. And he told me, and I just left, because you know, I just wanted him to tell me, so I just used whatever manipulation to get him to tell me, so that I knew who... I mean, he was the only one that I slept with when we'd used a condom and it broke. Yeah, it was like six months after I started having sex.

**BK:** What was it like getting diagnosed?

**P:** Well, my girlfriend that went with me – I had a girlfriend, I was living in a group home not far from the clinic that I went to, and she was so sure that I was going to be negative. I said, "You know, I have a feeling." I mean, I didn't feel – I kind of was ambiguous about it, I didn't feel one way or the other about it, but I just had a feeling that I was. I just, you know – so, I was ready for

it when I went in, I was ready for the doctor to say, yeah, you had it, because I had had so many disappointing times in my life previous to that that I was just like, okay, prepare for the worst. So, I kind of mentally got myself prepared for the worst, and when I went in, they told me that I was reactive, and I got a copy of the paper, because I wanted to have a copy of it – just, you know, for whatever reason, I wanted to have a copy of it. And I remember them telling me no fighting – they said don't fight, because it's blood to blood contact, and nothing else, really, because I wasn't in the risk category, right? And they didn't even really ask me what risk I was kind of at, or they didn't really – they said, “You're going to die in six months.” So yeah, that's my experience of getting diagnosed.

**BK:** Was there any connection to support or care at that point?

**P:** There was nothing, really, out there. There was nothing for women and there was nothing for youth, especially for youth – there was no services out there, period. So, I didn't really have – I mean, there was BC PWA at the time, but I mean, it was a gay disease, right, and it was gay men starting this organization, so I didn't feel that I fit in, so I just didn't go.

**BK:** I imagine it would have been challenging to walk into that space as probably the only HIV positive women there.

**P:** At that time, there was a few women that I know of that were diagnosed around the same time, but most of them weren't from here, most of them were in different ways, so I never really had contact with anybody like myself. So, I was kind of invisible for a long time and I didn't access any services for many years. But I was very young, I was very healthy, so I just lived life like I didn't have it, but only in the regard – well, I lived like I did have it only in the regard of keeping other people safe around me, and learning and being self-taught about it, so I just kind of looked at all kinds of information that I could find, and I phoned different places, and I just wanted to find out as much information as I could about it so that I could keep other people safe around me.

**BK:** Do you remember where you were accessing some of that information then?

**P:** Sort of, whenever I was in clinics or at the hospital or something, you could see pamphlets and stuff like that, so I would just pick up pamphlets here and there, and read them, store the information and get rid of the pamphlets, because I didn't want anybody to know I was positive. So, that's basically how I – and then I ended up getting hooked up with a doctor, Dr. [name] – she's now moved, she used to be a doctor many years ago, she's moved up in the administration at BC Women's Hospital. She took me on when I was about – I think I was about seventeen – and I saw her for a while, and I got tested again, because I was like, you know, maybe there's a mistake, so I went and got tested again, and there wasn't. Because they test you a couple of times to make sure before they put out that information. So, I saw her for a little while, and then just sort of – I ended up moving into my own – see, I was living on my own when I was seventeen. I'd just moved from the group home to my own place, and it was right after that that I was diagnosed. And I was just going back to school because I had quit school when I was young, and was just going back to school, to community college, and I was doing informal peer counselling training with different people in group homes, and I was doing haircuts. You know, I was just

starting to get my life back from my childhood being pretty traumatic and hard to deal with, and getting over that, and then finding out I was HIV, I just kind of went, ah, might as well just live life however you want to. I mean, it didn't really matter to do things to better my life, because I didn't think I was going to be around. So, I quit school again and went back on the street, and got into drugs, and mostly alcohol at the time. Yeah.

**BK:** So, that's kind of how you were coping with diagnosis?

**P:** Coping. I was coping with alcohol mostly – alcohol and marijuana at the time. And then I started to get into the cocaine pretty quickly. Yeah.

**BK:** When you're told you have six months left to live, I think it's a pretty natural reaction to say, well, I'm going to live it up then for that short amount time.

**P:** Yeah. I was still keeping other people safe around me, but I was like just party, you know? So, that's what I did.

**BK:** Where were you finding support at that time? Were there people that you talked to?

**P:** The only person that I told was just after I was diagnosed when I was sixteen, I told one of my girlfriends, another girlfriend – I told her, and she proceeded to tell everybody. So, I just kind of let it blow over, and people would ask me, "You know, I heard you are HIV." I'd say no. They said, "Well, you don't look like you're HIV," so it just kind of blew over after a few months. And everybody thought, okay, she looks too good, she looks healthy, she doesn't look like she's going to die, so she doesn't have HIV or AIDS, right? So, that was a support I was trying to get was through my best friend, and it didn't work out, so I was like, okay, I'm pulling back, I'm not going to talk to anybody about this stuff. My sister was the only one that knew, and she was kind of doing her own thing, and she had a traumatic childhood too, and she was on the street at thirteen years old putting needles in her arm, so she was in a bad way already. So, I couldn't really rely on her for any support, so there wasn't really any supports out there for me.

**BK:** You just kind of kept this to yourself and tried to get on with your life?

**P:** Yeah, just day-by-day.

**BK:** Was there any support from that doctor.

**P:** No, he was just a doctor at a clinic who told me my test results. It wasn't anybody I'd been seeing regularly or anything. I didn't go to the doctor too much before that – when I was living at home, I did. I didn't need to go to the doctor until after I was diagnosed, but I didn't really go to the doctor, I didn't think there was any need. The only medicine out there was AZT and I wasn't going to take that.

**BK:** There was awareness out there that AZT was not good.

**P:** Yeah, exactly. So yeah, I just – I didn't really see anybody after that, except for [doctor's name], and I only saw her for a little while, and then I just kind of disappeared into my own world, because there wasn't any medicines to take, and I was either going to be as healthy as I was – and I'd always been healthy through my childhood. Physically, I was always quite healthy and strong, athletic, so my body just took care of itself, so I didn't really have any issues with anything. And then when I lived to be eighteen and nineteen and twenty – I was like, okay, I'm not going to live to be twenty, I'm not going to live to be twenty-five, I'm not going to live to be thirty... [Laughs] And here I am.

**BK:** When did you start to come to terms with the fact that, hey, I have a lot more than six months to live here?

**P:** Probably in the late '80s, early '90s, when I was just as healthy as I was before, and I wasn't seeing any illness progression. I got hooked up with a doctor, my GP, probably early '90s, because I was pregnant a couple of times, and that's when a condom broke as well. I proceeded to tell the persons to get tested because I said I had Hep C, right, so I told them to get tested – I wanted to make sure that they were okay, and they were fine. It was only one person. And then I met a fellow that I had my daughter with – I had her in '93 – I met him in '88, and I told him right away, I disclosed right away to him. And we had protected and unprotected sex for many years, and I ended up getting pregnant, had an abortion, and then I got pregnant again, and I had her in '93. I couldn't do it again, I couldn't have another abortion. I thought – you know, I just couldn't do it, and I was with him for so long and I wanted to give him a choice too on whether I was to do that or not, and we decided against it, so I ended up having her. And I had her without any medicine – I didn't take any medicines – and had a natural childbirth, and she's fine.

**BK:** You were continuing to date a little bit and disclose.

**P:** Well, I was with him for many years, and then when we stopped dating, I met somebody else, and then I disclosed to him pretty well right away after we met, and he had actually had the same GP as me many years before, and he just knew about HIV and AIDS. He had had a close friend of his pass and he had disclosed to him because he felt he was the only one who wouldn't be judgmental, so he was self-taught about it, he already knew about it, so when he met me, he had already been educated about it. So, he kind of knew – it was kind of weird.

**BK:** How nice is that?

**P:** I know, but he kind of knew, so I didn't really have any issues when it came to that with him. We've been on and off for about twenty-two years, and we're on right now, so it's really – that was a real gift to get him in my life, for sure. He actually walked me to the front door of one of the organizations that I go to. It took until 1996 to actually get connected to an organization that's in the West End here, and I did get connected to the Oak Tree Clinic when I was having my daughter in '93, and then they connected me to an organization in the West End here. And I said to my partner, I said I really need to get some support. I mean, I'm not invisible anymore, I really need to get some support, and this wasn't until 1996, so he actually walked me to the front door and walked me in. He's negative – it's sure a different relationship.

**BK:** So, Oak Tree was the first sort of support?

**P:** It was sort of. Sort of-ish. Yeah, that was the first sort of connection that I had, and then they referred me to Positive Women's Network. As soon as I walked in there, that was it. They were like, okay, we want you to help us. I ended up getting really involved really quickly.

**BK:** What was that organization like at the time?

**P:** It just started a couple years before that, I believe. It was established, I mean, they had their own space in the building, but they wanted their own space, period, for women's safety, women's specific issues. Yeah, it was quite different. There was a lot less programs, a lot less stuff in place, but they did really well over the years. It's too bad that they're not around anymore.

**BK:** Yes, it really is.

**P:** I ended up doing a lot of volunteering for them, thousands of hours of volunteering with them. I did speaker's bureau, I did peer counselling training through YouthCO, I did speaker's bureau with Healing Our Spirit and went all on different reserves all through BC to share my story and stuff with them, and raise some awareness. Yeah, that was really good, especially with the youth, because I was so young when I was diagnosed, I just kind of wanted to get connected with the youth and get them to see what was happening and understand a bit more about people with HIV, so there wouldn't be so much stigma and discrimination attached. So, getting evaluations with kids, little kids, saying, "When I grow up, I want to help people with HIV," or "When I leave here today, I'm going to go home and tell my whole family about HIV." I was like, that's so great, because the stigma and discrimination is just so terrible, even now, today. I just can't believe it, there's still so much stigma and discrimination attached to it, it's just crazy, and I've worked so hard over the years to try to alleviate some of that in the community, and it's been so difficult. I just get angry when I think about it. I think about all the times and all the people who are out there trying to change that, and it's still so prevalent. And back in the day, it was like, they had posters – oh, I just want a hug. You can touch me. That was pretty unbelievable, but that was the way it was, right?

**BK:** What did stigma look like back then, back in the '80s and '90s?

**P:** Oh, you didn't want to tell anybody you're around anybody who had HIV, talk to anybody who had HIV – none of that. I mean, there was the myths of, you know – even today, if I was to go over to my sister's place, her husband would still – he would still wipe down the toilet seat and take spoons from me and wash them in the dishwasher as soon as I... He wouldn't let me touch any of my dishes, he'd take them and he'd wash them down right away, and sanitize them extra special – still to this day. I think some of it has to do with OCD in some sense, with germaphobic, but I can feel – I've been around for so long, I know when I'm feeling the stigma and if it's warranted or not, and discrimination. I feel it and I know if it's directly-related or not. I've got such a good sense of it that I can see it coming from a mile away. [Laughs]

**BK:** It's so discouraging that that's still so prevalent.

**P:** Yeah, so the stigma was really bad. It was just like you couldn't – like, part of the reason why I waited until '96 to go into an organization was because of that as well. My partner's family still doesn't know about me. My family does, but his family doesn't, and there's many people that I still haven't told over the years and still won't because of that. In the community that I live in, the rural community that I live in, if they found out, I can only imagine. I hope that wouldn't happen, but I know deep in my heart that it would, and I wouldn't deal with that very well. In regards to my addiction, I've learned all my coping mechanisms and learned to change them and deal with my stuff differently, but if that was to happen out there, I would get angry and I'd be like, here you go – I'd walk around to everybody and hand them out information, saying get this in your head, snap out of it, and hello, look at this stuff, learn something. That's what I would be like, and then I would move. [Laughs]

**BK:** Well, let's hope it doesn't come to that.

**P:** It won't because I'm very good at protecting myself and my anonymity over the years. I learned very quickly that that can be a big problem and being safe in certain situations.

**BK:** Do you feel that there was extra stigma, not just being HIV positive but being an HIV positive woman?

**P:** Yeah, most definitely. Like, just going into an organization that's down here as well, and it's a general organization – I don't know if I should say the name. Can I say the name?

**BK:** You're welcome to.

**P:** Friends for Life, and I went in there, and I had knapsack with me, and I was using at the time, but I try to keep myself – I never used in these organizations, I just used on my own and then would go there. And I went in there for lunch for one day, and I walked in and I saw a whole bunch of men walk past me and sign in and go through, and then I went in, and this fellow says to me, "Oh, you have to put your knapsack in the cubbyhole." And I'm like, "Well, what about these other five guys that just passed by me with their knapsacks. Why aren't they putting their knapsacks in the cubbyhole?" "Oh, we need you to..." I said, well, what's up? Why are the rules different for me or anybody else? What I'm feeling when I was going through that, what I was really, really strongly feeling was that, for one, that I was a woman with HIV; for two, on top of that, the underlying thing that was on their minds was that I was a drug user and they assumed that I got it through using needles, right? I never used a needle until 2000 – I used a needle for the first time, and that was when I found out I was Hep C positive as well. I just went, okay, that's it, I'm done now, because so many people died from Hep C, and HIV wasn't the killer, it was the Hep C, right? So yeah, I felt the stigma greatly then. And then of course, when you're in a group of people, like if you're going on retreats or going in a group of people, and you say how long you've had it, they just look at you like it's a contest or something. Like, "Oh, you've had it for thirty-two years? Well, I've had it for thirty-three." And I'm like, who cares? The only thing that – and also, I'm also like – it's like they don't believe me. Yeah, women got it back then, and youth. I mean there was nothing for youth for many, many, many years either. So yeah, I was

invisible for a long time, partly because of choice, and mostly because there was nothing, really no services directly for women and youth – young women.

**BK:** It sounds like once those services became available and you got connected to them, you got really involved.

**P:** For sure. I don't want to sound – I'm above intelligence for somebody with my education background, and I've always – my mother was always like that. She didn't have much of an education, but she was very well-spoken, she educated herself. She educated herself about my HIV when she found out about it, and addiction as well, so she was a lot like me. I sort of felt that survival instinct of needing to go out and self – you know, learn about it. I just sort of thought, okay, this is the avenue, this is the way for me to learn more if I get involved more. Things started happening where I was on the board of Positive Women's Network, and I ended up getting to go to conferences and stuff, health conferences, and learning, and Positive Gatherings and that sort of stuff. So, that's what I did to teach myself for myself as well as to teach others. So, it was a great opportunity to do that, going into the organizations.

**BK:** Did that become your community in some ways?

**P:** Most definitely. I mean, I've had close friends in my life, and I learned who to tell and who not to tell, and most of my closest friends know, but even that can still be quite difficult, to disclose even to somebody that you believe is a close friend and they love you and you love them. You know, but you have to weigh it out and you have to really know.

**BK:** You were going to conferences, you were on a speaker's bureau at Healing Our Spirit.

**P:** Because we were – back then, it was around new infections and people getting infected, and it was mostly young women that were being diagnosed, and most of them were on reserves, so I felt like I needed to kind of reach out and share my story with some women, young women, so that they would know how to protect themselves and harm reduction. I went out with YouthCO, I went out with Healing Our Spirit, we would all partner together and go out and do these speaks, and teaching partnerships. So, it was really, really – I just felt like I really needed to help other people not go through what I went through, and if they did, to know where to go and know how to kind of deal with it, and kind of alleviate some of the stigma and discrimination at the same time.

**BK:** It sounds like you were a real advocate for people back then.

**P:** Most definitely.

**BK:** That's amazing. It really is. That's incredible. And you still were a youth then, really, and you'd already been living with the virus for ten years almost.

**P:** Yeah, by the time that I was doing that, it was twelve years I had been positive already, by the time I started doing that. YouthCO let me do the peer counselling training at twenty-nine at the



very borderline of the cut-off because I really wanted to do it, and they allowed me to do it through them, so that was great.

**BK:** And they would have started up fairly recently before that too.

**P:** Yeah, that was all within a few years of that timeframe, a few years before that. I believe Positive Women's Network started '93 or '94 I think, and then YouthCO had just started probably around the same time – '95, '96 – yeah, something like that.

**BK:** And were you getting other types of support from those organizations besides going out on those speaking tours?

**P:** Well, I mean, I was tapping into the people that were there and being able to debrief and talk with a lot of staff. I was going to the food bank, I was doing the free clothing that they had there, yeah, the lunch programs – all those kinds of things. Just – they're important programs, but not like in-depth, like counselling or anything like that. It was more like just a need, a mild need for food and stuff like that that I was getting.

**BK:** And then making new friendships and meeting new people, I guess.

**P:** Absolutely, networking, sure. I met a lot of women, good women, and you know, I heard a lot of stories. It was good to be able to connect with some women that were positive for so long too, because I could understand where they were coming from and learn something about their stories, so that I could share as well with other people. Not specifically, but share our stories with other people.

**BK:** And to not feel like you're alone anymore as the only positive woman in Vancouver, it must have felt like for a long time.

**P:** [Laughs] It sure did. It did.

**BK:** That must have made a huge difference.

**P:** It made a huge difference, for sure. It made me feel – you know, I was very active, so it was very good to have that feeling of confidence and feeling like you're doing a good job. A lot of people, when I hear stories and I talk with people all the time – like, I do it all the time. I've been doing informal peer counselling for twenty-five years, so I hear stories all the time about people – what were just...? Oh, my brain just lost it. I just lost that train of thought.

**BK:** You were just talking about being a peer counsellor.

**P:** Yeah, I've been doing that for a long time. I was going somewhere else with that, I just sort of lost that. Sorry about that.

**BK:** That's okay. So, did you stay quite involved with those organizations as we move toward the 2000s?

**P:** Yeah, I ended up getting hooked up with the Dr. Peter Centre in the late-2000s, yeah. I was incarcerated a couple of times over the years for different things, and that's – when I was incarcerated, a lot of people found out I was positive when I was incarcerated, on the street especially, because I was... I ended up almost dying in 2010. I was in addiction from – see, I'd done really well from like 2001 to 2005, and I'd done all these – the volunteering and got involved with PWN and doing all of that, and then I sort of got burnt out. And I was working part-time, and I quit my job, and I finished my tenure at the network, and I made some bad decisions and ended up homeless on Hastings St. for another five years after that. So, when I went to jail, before that – yeah, it's not easy. You can't keep it quiet in jail, everybody knows because you go up to the medicine, you go up to the nurse's station to get your medicine with everybody else every day, and people just know, they find out. Like, nobody even knew my real first name or last name until I went to jail, so nobody even knew who I was on the street until I went to jail, and then they knew I was positive, and they knew all my information as well. And the guards treat you differently too.

**BK:** So, just a ton of stigma in that setting.

**P:** Oh, huge. But because I am the way that I am, and I am so – I don't take crap. [Laughs] And they even told me when I went in, who was it that told me? I think it was the nurse that told me, "You might not want to tell the guards." And I said, "Well, they're going to find out anyway," and they found out, and they actually – because of my kind of active way and because I was always doing peer counselling, even while I was in there, they were kind of happy to have me in there, because I was able to teach them about it, because I was like, okay, everybody knows about it anyway, so I might as well teach, help. That's what I did.

**BK:** So, you found yourself being an advocate again.

**P:** Always. Always teaching, always advocating.

**BK:** Was there any education programs or outreach programs in the prison around HIV?

**P:** I actually did the prison outreach program, went out to the jails with BCPWA before they changed – now, it's no longer, which is crazy.

**BK:** The program?

**P:** The prison outreach.

**BK:** It's completely gone?

**P:** There's still – out in Surrey, there's still a connection with one of the – Jim Pattison, I think, they have a clinic there that somebody works out of, but there's only one person doing it, and there used to be several of us. I remember I used to drive a woman – she has passed now, a really elderly woman – she was really, really cool. It was like *Driving Miss Daisy*, she was so cute, she was this little old lady, and we'd drive in there. We'd walk into the men's jail, and this was after

I got convicted of crimes, they actually still gave me the security clearance to go into the jails, so I was really quite surprised that even happened. But it's funny, we'd walk in there and the guys would be all happy, and they'd be like, "yeah!" And they'd see [friend's name] and they'd be like, [groans]. She would tell everybody this, and just, "Oh yeah, they see [interviewee's name] and they're like [gasps] and then they see me and they're like [groans]." [Laughs] It was so cute. So, I mean, I accessed the prison outreach program when I was in jail because they would give you protein powders and vitamins and stuff like that, but I don't believe there's much programs happening in there in regards to HIV anymore. I mean, they get their medicines and stuff like that, but even that can be really, really bad too, because when I went in, I was on medicine and I didn't get it for weeks after I got in, because they had to put in a request and do all this stuff, and it was just crazy, so I had to do without. So, I just stopped doing it for a couple months longer and told them hang onto it, I'm going to take it, I just don't want to become resistant to it, so I'm going to stop for a couple of months, and then I'm going to go back on it again, and then they can blood test me and see if it's working, right? But a lot of people don't know these things, they just don't know about the resistant concept with HIV and medicines. I knew all that stuff, because I was out there doing it all and understood it very well.

**BK:** Sounds like you had a lot of expertise on a lot of these matters. That's incredible.

**P:** Yeah, I'm very, very thankful that I've got my mother's genetics, and I'm just out there, you know, doing what I have to do, and my survival skills are so in-tune. Yeah, I'm a great survivor of all things, you know? I don't toot my horn very often but... [Laughs]

**BK:** No, I can certainly hear that from your story, and the resilience on so many different levels. It's amazing. So, you started on treatment eventually?

**P:** I started on treatment probably... I don't even really remember. I think it was... [long pause] Probably '99, maybe 2001, something like that – around 2001, and I tried, but I was on – when I was on the street and using, I stopped doing street work because of the HIV and the criminality, and I knew back then that was no good, and cops would give you a hard time. I wasn't interested in any of that, so I found other ways to make money. But I couldn't keep to the adherence, so I would start on a drug and then I'd stop, and then I would start and then I'd stop. And when I got a place, I got some subsidized housing in 2010 straight from the hospital, because I was in the hospital. I was really sick and I almost had kidney failure because I had a couple infections in my body that I didn't know about – the one was a staph infection, it just started, and the other one was a strep throat infection, and I didn't know that I'd had either until I was – you know, I started blowing up with water, and I went, okay, I need to get to the hospital. So, I took a bus from downtown, from the eastside, and I walked into St. Paul's and I said, "There's something very wrong with me. I need some help." And they took me in and admitted me right away, and they told me if I hadn't come in within twelve hours, I would have been dead because the poisons and toxins in my body, my kidneys were giving out. And I gained fifty pounds in water in thirty-six hours, almost two hundred pounds with all the water gain.

Yeah, it was pretty scary, but I came out of it, and within five weeks, I was okay, and I was out of the hospital. And I started on medicine again pretty much at that point, and my Hep C was really bad at that point, I started going downhill with the Hep C. I did have water gain, but I did

get drained for the water in the hospital. And then I moved into some housing, which was a huge barrier, and I needed it and I got it. But the Hep C kind of took over my body, and with some of the medicines I was taking, it was harder on my liver than I would have liked. And I was still using a little bit here and there, but it wasn't too bad. Like, it wasn't – the housing made a huge difference on keeping me wanting to get sober. Yeah, so I started taking – I tried a couple different kinds of medicines, and I sort had some side effects from them. I took Sustiva, Trizivir, there's... DDT – I'm not sure, I took a few of them. I was like, okay, the side effects are too much, I don't want to do them anymore. So, when my liver started getting really bad, I think it was 2014, there was another drug that came out, Triumeq, around that time, so the doctors wanted me to get on the Harvoni, but the Harvoni wasn't approved yet, so they were going to apply for it on humanitarian grounds for me. So, they started to put me on the Triumeq because it worked really well with regards to the side effects with the Harvoni, like you wouldn't suffer very many side effects in taking the medicine, so I took the medicine and my body did really well with it. And I was undetectable in a very short period of time.

So, in 2015, I had to move from the housing because there was a big problem there and there was some discrimination about me. It was HIV-specific housing but when I moved in there, I think that they thought I was gay, and then when I ended up being straight, my partner started coming back around – yeah, I felt that really strongly things drastically changed when he started coming around. And I'm always very active and they had a camera on my door, and I wasn't doing anything more than – like, so many other people in the building were just doing so many more things, and they were just really watching me, and it was really, really – and I was pretty much sober at this time, so it wasn't like a psychosis or anything was getting in the way. I could see the camera moving on my door, and then the manager called me one day when a friend of mine was doing Hep C treatment, he would just come into my place on the weekends and he would just give me the money for the accommodation fees that he would get from the government, so he'd give me the money and just stay at my place, right? She phones me at 6:30 at night and asks me, “Why is this person walking into your place with a suitcase?” I'm like, why are you calling me at home at 6:30 at night asking me this because you're looking through that camera and you have instant CCTV access to these cameras, and this is ridiculous.

And I just can't keep my mouth shut sometimes, so eventually they found reasons to give me a hard time, and I ended up signing a mutual agreement just leaving my subsidy, because they wanted me out so bad, because I was just raising all these issues, and legal issues that they were having with tenets being security – they couldn't pass a security test if their life depended on it. And just different things were happening, and they had a superintendent there that was on drugs, and I'd watch him walking up the street when I'm in my suite, I could see him walking up the street and scoring dope and coming back, and hanging out in empty apartments and getting high, and all this stuff, and I was just like, no, I can't deal with this. But yeah, so I ended up leaving there, and I started the medicine right before I left, and my doctors were freaked out – I had Dr. Hull as my Hep C specialist, and they were freaked out because they thought that, you know, this was going to cause me problems mentally, and I was going to be feeling suicidal and all those things that happen when you're taking the Harvoni. And I was like, no, I feel fine, I can do it, I can do this. And I ended up getting through it and now I've been clinically cured for over two years – two and a half years now.

Yeah, that changed my life completely – 100% changed my life. Now I have the energy, I was able to get rid of some of the water gain. My spleen – I still have side effects from the liver disease, because my spleen is like twice the size it's supposed to be, and my liver, if I do any. Like, I was doing a serving job for about a year and a half, and that pressure of my spleen being swollen on all of the other organs really caused me a lot of pain, so I realized I can't do physical labour. So, I had to quit that job. I've moved three times since – I've actually moved more than that. In 2014, when I lost my housing, I moved five times in a year and a half because I couldn't find suitable housing, and I spent any money that I have in my savings, gone, moving and all that stuff, and damage deposits, because I ended up having to leave places without giving notice, because physically if I didn't – you know, it was horrible. So, here I am today.

**BK:** And today, you're feeling a little more settled?

**P:** Well yeah, I found a job here in Vancouver doing some outreach work, but it's only a couple days a week. So, my partner's got subsidized housing, just got it, so he was in an SRO for two years – like, I chose to live on the street when I was homeless because I didn't want to live in any of those hotels, so I can't imagine doing it again. And he was over at my place a lot of the time, weeks at a time, but he got subsidized housing down here, so now I just stay at his place a couple days a week, and I work, and go out to my place on the weekends. So, this is the kind of job that I like. This is the kind of job that I've been waiting for for thirty years, and I knew it was going to happen eventually. PWN had a peer navigation job posting before they closed and I signed up for it, and I know I would have got that position, but they ended up closing. I'm like, all of a sudden, you're closing? What happened? And I kind of found out some stuff – I have a much better understanding of why they're no longer. But yeah, this is kind of what I've been kind of waiting for is this kind of work to help people who are newly diagnosed and maybe aren't newly diagnosed and just need some help navigating themselves around the system, talking to different people. I've dealt with social workers – when I was fifteen, I was doing workshops with them on how to deal with teenagers. I mean, this is stuff I've been doing all my life. It's nice to be able to get paid for it and get equal pay. I've been fighting for that for twenty years too – equal pay for people like myself to do this kind of work. The healthcare system could have saved themselves a lot of money if they'd just done this twenty years ago, but better late than never.

**BK:** Because you're the experts, right?

**P:** That's right. I'm not putting anybody that went out and got the education and all of that, I think that's great – I would have loved to have had that too, it just didn't work out that way in my life and the way it has been. You know, I respect and I appreciate anybody who educates themselves and goes to school and does all that stuff – I think it's great and I wish I had had those opportunities, because who knows where I would be today. But I'm happy with where I'm at.

**BK:** And what does HIV mean to you today?

**P:** Ah, that's the point I was trying to get at is people would say HIV saved their life – getting HIV saved their life because the lifestyle they were living was going to kill them. It didn't save my life. [Laughs] It absolutely ruined my life. I had just got my own place, I was seventeen years

old, sixteen years old when I seroconverted, but seventeen years old... I'd just got my own place, I was living on my own, I had finally left all of the crap behind from my childhood, and I was dealing with that and learning how to deal with that and cope with some of the feelings and stuff like that. So, I got my own place, I'm living on my own, and I'm going back to school, and I'm doing all these things with the group homes, and still doing haircuts – you know, I've got things going on, right? I'm doing great, and then I find out that I'm HIV, and it all went to shit. So yeah, what does HIV mean to me right now? Is that what you're asking?

**BK:** Yeah?

**P:** What does it mean?

**BK:** Like, it's not the same as when you were diagnosed and told you have six months to live.

**P:** Yeah, I'm on the fence about some of the stuff that I hear about HIV and being a manageable disease. Okay, for me, when I'm not in addiction and I'm doing well and I've got all the supports in place and I'm accessing them, HIV is manageable, right? But for some people, when they've got all their stuff going on and they're not able to cope, HIV is not manageable. So, I'm on the fence about that one. It depends on where you're at – if you're on the right medicines, if you've got a good connection with your doctor and you work as a team – all those things have to come into play before it can become a manageable disease. So, when people say, oh, it's a manageable disease, I just cringe, because... I mean, it can be with all sorts of different diseases too, right? We live with diabetes, with cancer, and some things can be managed and taken care of and treated, but if you're not living the right lifestyle or eating well, and doing all these things, it can overtake you and make it unmanageable. But it just – I don't know, I guess I'm kind of stuck feeling really bad for other people that aren't in a situation where they can say their life is manageable. So, HIV to me, I've never identified as an HIV poz – like, "I'm HIV" or "I have HIV?" That's how I identify – I have HIV, and I don't always identify with HIV first. I mean, I identify only in my work, with people that I know in the West End here. And where I access services, everybody there already knows you're HIV, you don't have to say it, right?

So yeah, HIV to me – it's hard to say. It still means so many negative things. It still means – the discrimination is still so huge and the stigma attached is just – it doesn't... I mean, there's been some headway, quite a bit of headway, but only if you're already in the community. I mean, being in a rural community, I've had experiences out there that – I realized that there could be huge problems for people until – I mean, I didn't really know how it felt until I experienced it for myself. And that tends to be the issue for a lot of people – they don't understand things until they experience it for themselves or if they're really directly related or affected by it, and that's really sad. And I even find that for myself. Like, going out to the [city] hospital, my GP had a GP covering for him, and because my CD4s have always been quite low right from the start, she freaked out and thought that I – because my CD4s are below 200 and I'm not on Septra or anything like that, because my CD4s have only been – 550 is the highest they've ever been since I was diagnosed, so I've always been on the low scale anyway. She freaked out and thought I needed to go get some antibiotic treatment, phones me up and says, "You gotta go to the hospital! You have to come into the office first." So, I'm at home, I'm like, okay, I'm coming in. So, I get in the car and I'm driving in to go to the office, because I'm think she's going to talk to

me and she's going to tell me something I don't know, and then changes her mind and phones me and says, "No, no, just go to the [city] hospital."

So, I turn around and I'm in Surrey by this time, so I turn around and go into [city] hospital. And there's this woman there, I remember sitting in one of these waiting chairs after being brought in from the front waiting room, and I've got people around me coughing and hacking, and I'm just like, can I have a mask? Can you sit me somewhere else please? If I've got a serious issue that I have to have – I can't remember what they call the condition, but anyway – it's like when you have too low of a CD4 and they want you to get antibiotics to help like a prophylaxis, because I wasn't on the Septra. So, I was freaking out thinking if I breathe in one thing, it could kill me, right? I asked this one nurse, "Can I sit over there," you know? She goes, "Oh no, this is the only seating available." And she proceeded to walk over to this woman at the desk, and she looks over at me and says, "She's HIV." [Whispered] And I could read her lips, and I go, oh great. The other girl, she just looked at her, she goes [shrugs] and then went to her typing, like who cares type of thing, right? And then there was another time I went into the Life Labs out there to get bloodwork done, and this one woman wouldn't even take my blood, and I was just like, oh my god, this is crazy. I need to get out of here, you know, because it just makes me so angry.

So yeah, HIV still means great stigma and discrimination. And you know what I just found out too is that people who get HIV aren't necessarily going to get approved for any disability benefits, provincial disability benefits now. So, I'm just like, hm, okay, so people who are out there and putting themselves at risk – maybe not putting themselves at risk, maybe they've just been in a situation like I was in – they may not even get disability. So, that's the manageable part of it, so it – I don't know, it's hard to say really what it means. It's just from one extreme to the other, there's still so much stuff happening in regards to it. These doctors – there's so many doctors and nurses and people that need to be – they need to understand more about it, because what about these people out in these areas who don't have a peer navigator to help them or don't have – like, they have these services, but they're so periodic that there's nothing really set in these places that can reach all of these people. And sure – I have a girlfriend of mine that was living up in northern – like the tip of the island, and she came down here for services, because she was HIV positive. This was a while back, and she got into drugs. She'd never been around drugs until she came down here for treatment.

So, don't you think it would be better if there was something out there for people to go to and that there was relatively people with sensitivity training, some more of that stuff happening in the healthcare system? I don't know, there's just so many more things that can be done, because there's still lots of infections happening, and it's not going to help the healthcare system with all that happening. If they could just find a way to reach some of these areas – always thinking about that, you know? Like, having a peer navigation registry and just putting the dollars out there, and having a peer navigation registry of people in the area that they can call and say, "Can you go and see this person, right? Where are you right now?" "I'm in Port Alberni." You know, "I need you to see somebody 100 clicks from there. Can you go and talk to them?" Just have that pool of dollars to have like a peer navigation registry with connections to social workers or people who are sensitive to it in those areas, so they can connect people in a confidential way. We're getting a bit off topic, so... [Laughs]

**BK:** No, this is completely on-topic.

**P:** Yeah, all of that, you know? There are so many different ideas. I wish that... And now that the opioid crisis is happening, it's taking away all of the dollars from all of the other stuff. There's people that are losing funding and organizations that are having programs cut, and I understand that there's a huge opioid crisis out there, and that's not helping with the HIV infections and Hep C infections. Just when we start to get somewhere in the HIV community in that regard, then something else happens to suck the funds out. I'm not saying that it's not legitimate, it's not a crisis, and it's not needed, it's just that there always seems to be something happening. And I think – I think it's really good that there's funding for peer navigation and outreach workers and the RAAC [Rapid Access Addiction Clinic] program at the hospital there, the STOP [Seek and Treat for Optimal Prevention of HIV/AIDS] team – I think it's great. I mean, I'm working with the STOP team now, alongside of them, because I met a couple members of the STOP team through my girlfriend who just passed. She had had a couple of members of the STOP team visiting her and taking care of her and helping her, even though she was very good at self-advocate, I found myself working beside them after I had met them with her, and all of a sudden, I'm working beside them now. So, it's quite interesting – yeah, they're really good. She was very fortunate to have people like that in her life, and I'm really thankful for that, because when I couldn't be there, they were – they were very connected with her. Any other questions?

**BK:** We've covered a lot. The other thing that seems to be an issue with the erosion of some services is this idea that HIV is over almost. And that is just so not true.

**P:** It's so not true. I was just at a lunch and learn – they have them at the hospital in one of the theatre rooms or whatever, and I was shocked. I was there for a syphilis workshop, syphilis and gonorrhea, and they were talking about that, and I was like, oh my gosh, there's an open door for HIV as well, right? And there's a lot of people who already have HIV that are getting these diseases, and then, oh my gosh, even though it may not be the HIV that's the cause – they're getting a lot of these other infections because they have the HIV, right? And a lot of them are being spread easier to people who are HIV. So, there's all this – all these layers to it now. So, I don't know. There's not enough – it's not over. It's not over. There's still a lot of young people, young men, young women, people on reserve – like a lot of people, like I said, they'll leave their rural communities, come to Vancouver for help, or they'll come to Vancouver for whatever reason, of visiting friends or – they end up in addiction and they get HIV, Hep C, and go back to the communities, and because there's so much stigma and discrimination attached, they're not going to tell their communities, and then they spread it, and then more and more people, more and more people. So, it's definitely far from over. But I remember, was it on the news, they were saying something about a couple people being cured. It's like okay, maybe I'll be around. I was around long enough for a cure for Hep C, so who knows? You never know. That might be interesting to see something like that play out. I'm not pinning any hopes on it. [Laughs]

**BK:** We'd all love to see that.



**P:** A lot of pharmaceuticals would be very unhappy. They're losing all their funding, no money coming in, because the HIV drugs are probably a big chunk of their profit all around the world, and in Canada and the U.S. too. In the U.S., prices are through the roof for all of these medicines.

**BK:** Is there a need for another women's group here as well?

**P:** Absolutely. There's a bit of a grassroots movement that's happening right now for – by and for positive women, so we're hoping to eventually, over the next couple of years, have a replacement for PWN to some degree, but that won't be happening right away. Just trying to get it together, and there's an online group right now – I'm part of the committee, the standing committee for that.

**BK:** Is that VIVA?

**P:** Yeah, so we're trying to figure out some ways for fundraising just for – I mean, we're sort of an umbrella under Positive Living right now, so I've never really liked that idea, but what can you do? But we have to be strong enough and be able to be in a place where we can start on our own eventually, so I think that's in the plans.

**BK:** It would be great to see that happen.

**P:** Yeah, it would. I'm more than happy to be part of the standing committee for that. They were so happy when I started coming back around. They were like, "Oh my gosh, [name], you're back, you're alive." You don't know how many times I've heard that – "Oh, you're alive." People thought I was dead, right, because I just kind of went into recluse because I was so sick, and I'd done so much work in the 2000s and just kind of... But I'm stronger than ever now.

**BK:** I'm just about out of questions. We've touched on all of this already, which is great. Thanks so much. But we always like to ask at the end of the interview what advice you have as a long-term survivor for folks who are newly diagnosed today who didn't live through this period that you've lived through. What advice do you have?

**P:** Number one, HIV isn't a death sentence – if you treat yourself right and you make healthy choices and you're physically active and mentally active, then you'll be okay. I think that that's a huge one, yeah, that it's not a death sentence, it's not like it used to be, and a lot of the medicines are really refined a lot better than they used to be, so it's okay to take medicine, it's okay to... And U = U, right? U = U is huge, you know, undetectable means untransmittable, and that there are criminality situations attached and you have to know your rights and know the law around disclosure and what your responsibility is. Keep an open mind, and keep yourself safe as well. It can be dangerous, disclosing. There's always ways of dealing with that kind of thing if you need to – there's supports in place.

**BK:** Especially as a woman, disclosing.

**P:** Most definitely, yeah. I remember being – like shaking, thinking to myself I have to tell this person, shaking. And I'm strong, I'm a big girl, I'm powerful, so you know.

**BK:** And that message around U = U, that's such a powerful...

**P:** Yeah, it's amazing. I'm so happy about that, U = U. There's still some finer details I'd like to know about before I feel entirely safe about putting somebody, like my partner who's negative, at risk. Like, there's still some little things that I'd like to know about – and just information in general. Like, for some people, there's other things going on – there's herpes and stuff like that. What in the study – did any of that get brought into the study? Was there people with that in the study that were going through the study and having unsafe sex? What were the...? Yeah, it would be interesting to see a bit more study, a little bit deeper around those kinds of things, around transmission.

**BK:** That message has the potential to chop off a lot of the stigma hopefully...

**P:** Well, wouldn't it? But everything's always too far behind in the times, everything takes too long for me to get out there. It seems to take – it's just like we're behind the times. From the States to here, we're about three or four or five years behind, and with the HIV movement, we're always years behind in everything we're trying to do to eliminate stigma and discrimination. Even with that happening, people will just be like, "U = U? What the hell is that? Really? No way. You've gotta be kidding me. No way." Because everyone is used to that old story of way back, you know? It's actually quite a fragile disease, virus, and people don't even know it. Yeah, Hep C is a much stronger virus. When I was diagnosed with Hep C, they believe that I got it when I seroconverted, that I got it at the same time, because the HIV masked it for many years, so it was in my body and I didn't even know it. But if I had it for the same amount of time, that's why my liver was taking it so hard, because I had it a lot longer than I thought.

**BK:** If there are still nurses or staff at Life Labs who are afraid to take blood from HIV positive people, we've got some work to do still.

**P:** I know, I know.

**BK:** That is horrifying.

**P:** I know. After all these years. It is horrifying. And it was funny, because it was the older lady in the emergency that was talking to the younger one, and the younger one was like who cares? And it was the older one who was like, "Oh, she's got AIDS." What's wrong with this picture? The good thing about that picture is that the young people are hip to what's going on and they know, and it's the older people that need to get retrained, right? They need to get retrained. I'm like – I remember I had an injury on a bus, and I went and I claimed – I made a claim and I went to ICBC, because I believe the person on the bus, because I was talking to the mentally disabled people at the front of the bus, and every day I got on the bus, I'd talk to them, "Oh, hi..." And I think because I didn't look physically disabled, because I had a yearly bus pass, and I think this bus driver thought I was mentally disabled because I didn't look physically disabled, and I'm just kind of assuming, but I had a strong feeling, because when I got hurt on his bus, it was his fault, and when I went to ICBC to talk to the adjustor, he goes – no, I said to him, "You know, I know some people. I've got some connections. I can bring some people in to do some sensitivity

training for you guys if you'd like." [Laughs] Because this person needed to obviously realize some things, right? It's pretty funny.

**BK:** And you're still doing this work, you're still pushing this forward, and thank you for all the work you're doing on that. That's amazing.

**P:** Doing my best. Thanks. I appreciate that.

**BK:** I think I've asked all my questions. Is there anything you want to add before we turn off the recorder?

**P:** Okay, so with the survivor study, what are you guys aiming to do? Like, what's your end game with all the stories that you're getting? Like, what are you wanting to do?

**BK:** The biggest thing at least immediately is to get all these stories into this archive, and it's going to be more of a community-oriented archive, so it's going to be a bit more engaging. And people will be able to click on different interviews and watch some of them or listen to some of them or read some of them, in your case. And we'll pull out a few parts that we think are more important.

**P:** So basically, it's more of trying to alleviate some of the discrimination and stigma attached. And maybe people who are positive who want to look at – is it just for people who are positive or for the community in general?

**BK:** Well, it's for anyone who wants to look at it.

**P:** That's great.

**BK:** The folks who we have talked to have either been caregivers or long-term survivors like yourself.

**P:** Well, that's really good.

**BK:** And I think the other thing, like we talked about earlier, is that long-term survivors still have needs in terms of care that are not being met anymore.

**P:** Well, I couldn't work full-time if I wanted to right now. So, if I didn't have my benefits, I'd be in big trouble. There's just no way, because I still have all of – I'm advanced HIV, I'm not just HIV. I'm not just diagnosed and seventeen years old anymore, so I don't know, it's going to be pretty scary for some of these people who aren't going to be able to get any benefits to help them. What's that going to create?

**BK:** And maybe not access to the supports that were there in the past because a lot of those programs aren't there.

**P:** Right, because a lot of the funding is gone. Yeah, a lot of them are gone. So, there's so many different things to be worried about. Like, for me, I'm okay. I can deal with my stuff and I can advocate for myself very strongly, but for some people, they might not be able to. Yeah, I guess that's what I'm doing for work now [laughs], so I can help them with that.

**BK:** So, I'll just stop this for now.

**P:** Sure, that would be great.