

“HIV in My Day” – Interview 58

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

Interview anonymized at participant’s request

Ben Klassen: Thanks for being here.

Participant: You’re welcome. Thanks for having me.

BK: We’re grateful for you to be here and share your story with us. Just to get started, by way of an icebreaker, when did you first start getting involved in the gay community or start engaging in gay life so to speak?

P: In my early twenties when I moved here, because it was very – well, back in the ‘90s, you could actually go almost anywhere and meet some guy for sex in the ‘90s, way back then. Now, it’s changed a bit, now it’s more online, but back then it was more like go down to the Aquatic Centre or... Yeah, so I’ve got stories. Crazy. So, I guess I became HIV from practicing non – well, practicing unsafe sex, that’s how I got it because I was pretty – my hormones were really driving me to have sex.

BK: Probably an exciting time.

P: It was, yes, it was an exciting time, so it’s fine. It was okay until I became positive, but that was something different.

BK: And you got to Vancouver in...?

P: 1990.

BK: So, before that, there wasn’t a lot of connecting with gay communities?

P: No, I grew up Catholic, so it was pretty much off the table. You didn’t talk about anything like that – not even that – especially going to church every Sunday morning, so you didn’t talk about it. It was a pretty tough struggle. Being in high school, it wasn’t the easiest in high school. I was pretty much a loner.

BK: So, is that part of what motivated your move to Vancouver then?

P: Yeah, because I heard it was a lot more openly gay, it was a lot more accepted here, and I’m like, okay, well, might as well try it out. And the sex work was pretty good here too out here back then. Yeah.

BK: Any other reflections on what the community looked like in those early years, in the early ‘90s in Vancouver?

P: Way different than it is now. There wasn't as much support as there is now. I do remember, like, I never went to UBC, but I used to go to the gay club or the gay group they had there at UBC back in the '90s. I don't know if they still have one there, but back then, it was – I'd just met some guys at the bar, and they said there was a gay club at the university, and it was like, okay, might as well try it out. It was okay. Of course, it was more meeting for sex again [laughs], but at the university.

BK: Another place to cruise.

P: Exactly, so there you go, right? It was okay.

BK: And did you get involved in the bar scene or anything like that?

P: Oh yeah. Oh, totally. Yeah, I used to go to the Dufferin a lot or the Royal – they used to be on Granville, which is now a hostel now, but they used to be the gay bars. But the Dufferin was one of the ones – Davie Street too, so there was a lot more happening back then gay-wise, a lot more gay clubs than there is now. So, it's – I don't know how the twenty-year-old gays – it's way different than then when I was in my twenties in the '90s – it's just way different. But you just had a good time every time you went to the bars.

BK: I guess we can bring HIV into this picture a little bit. When did you first hear about HIV?

P: Oh, when I was in grade eight – no, I was in grade nine. It started coming out on the TV, and of course there were articles in *Reader's Digest*, but that's something my family never really listened to. But at school, for sex ed they got that involved in the early, mid '80s. They wanted us to do a report from what you hear in the news or whatever magazines there were. And I kept saying I'll never become positive, but gees, I became positive. It was pretty scary back then. People were dying very quickly, and then all of these famous people started coming out and dying of AIDS. I was just a teenager, so it didn't really faze me, I just learned from it at school and that was basically it, and whatever the news, you know?

BK: When you got to Vancouver, was there information here at all around HIV?

P: A little. Not as much as there should have been, right? A lot of guys just didn't want to use condoms – it was weird – they just didn't like the feel of it. So, it's like, okay, whatever. I always wanted guys to use them – I would use condoms, but then, no, whatever. So, I guess I should have known better and walked away, but you know. If you did your research, there was books on it at the libraries, and sure, at universities, but it was still something new.

BK: So, there might have been some information about safe sex out there?

P: There was always information about safe sex, but it was more guided toward STIs back then, they really never thought about HIV or AIDS, but it was more toward STIs. Yeah.

BK: And then actually negotiating to actually use condoms – a challenge.

P: Yeah, a lot of guys didn't want to use condoms, so I was like, okay, whatever. They just said they didn't like the feel of it. I'm like, okay, whatever.

BK: Also thinking about those early years, was HIV something that was visible here in Vancouver? Were you seeing people who looked sick, or were you hearing about people who were sick here in Vancouver?

P: Yeah, there were people who you could physically tell, people on the tenth floor at St. Paul's, because medication was not really available – there was, but it was really hard on the bodies, people's bodies. Some people just chose not to use medication because there was a lot more side effects then, and just being HIV positive. Yeah, it was pretty rough, really crappy to see people die – becoming your friends and then just... wow. But we've come a long way from way back, like thirty years ago when it first came out.

BK: How was the community responding in those early years?

P: There was a lot of stigma, for sure. Lesbians were – it was just weird, because lesbians never associated with the gay guys. I'm like, okay, whatever. Times are different now, but there was a lot more stigma, a lot more discrimination back then, but there's still discrimination now. But it just seems like back then people thought they could just say or do whatever to someone who appeared to look sick. It could have been cancer, not HIV, but because of the media, it was a lot more a gay man's disease at first, and now it's... Just because someone had cancer and HIV, they might look the same, but they're two different diseases. It was because of the media, just think that someone with cancer has HIV, and stop discriminating against them.

BK: So, even within the community there was a lot of that negative...

P: Oh, sure. It's pretty sad though. Sometimes I wonder, it's probably a lot of fear, because HIV wasn't really known – it was only known to kill people, it was almost like a death sentence. Now, these days, there's a lot more support compared to back then, and now it's not just gay men who have it, so it's a variety of different types of population, right?

BK: Do you feel like the stigma around HIV has changed a lot or not so much?

P: No, it's still there. People are still afraid of having sex with someone positive. But to me, they're just totally uneducated. It's like they need to get educated on the subject. I know men in their sixties and they're like, "I don't want to touch you. You're HIV positive." And I'm like, come on dude – like, weird. But there will always be stigma, no matter how much people are educated, there will always be a group that chooses not to, I guess, educate themselves.

BK: As the '90s progressed, did you find yourself having access to more information around HIV?

P: It was getting there, because I got tested – I found out when I got tested at Three Bridges, and that's where I found out. It was really crazy though, it was really creepy. Well, it's just something that you don't want to hear, and you don't expect to hear it, so they did another test

just to make sure. Yeah, it's pretty – it was pretty shocking when they told me. And for the longest time, if I was on the bus or SkyTrain, I would be like who else on here besides me is HIV positive? Even though it didn't show at the time, which was kind of good, for the longest time I thought about that, right? But now it doesn't faze me. It was pretty tough. It wasn't the easiest thing to live with, but then I got sent to Spectrum Health, which they had really good doctors there. I had my doctor for like fifteen years – she just retired last year. Now I have some young little medical doctor from graduate, and who's a little too eager [laughs] – it's like, oh geees. It was pretty tough back in the '90s, and as time progressed, there was more and more education, more and more literature. The medical field was doing a lot more – more advancements, getting on medication for ARVs and different types of – I guess they called them cocktails. Much better now. I was very lucky. The only – I was on three different cocktails, and the only side effect was that there was just really bad vomiting, so I was pretty lucky. That was the only side effect I couldn't handle. And then another one basically gave me – it looked like I had jaundice because the whites of my eyes turned yellow, and I was like, I don't want that. And the doctor was like, oh, just say you eat lots of carrots, and I'm like no. And now I'm just like on atripla, which is three medications, one pill. I've been on it for at least ten years, and it's – the first few times you take it, it felt like I had vertigo, because the room would be spinning, but now when I take it, I take it at night time, and it helps me go to sleep at night. It works for me. I've been undetectable for like ten years, so to me, it's just like an extra sleeping pill – I just take it at night before bedtime, and when I start getting drowsy, I just hit the bed. It's pretty good. I like it. My old doctor wanted me to change, and I was like, well, why should I change? I've been on it for a long time and I'm doing well, so why would you change it for something different? She was like, "Okay, just keep reminding me that you don't want to change." And I was like, okay, I will. It's pretty good these days now – pretty good.

BK: One pill is a lot more manageable than some of the ones...

P: Yes, because I know people who got it in the '80s and they're like on between five and ten pills twice a day, but they also over the years got other conditions. But I'm lucky, you know – I count myself lucky – just one big horse pill, which doesn't matter to me. And it's easy to take, so yeah, it's been easy.

BK: You got connected to Spectrum right after your diagnosis, more or less?

P: Yes, right after diagnosis, through Three Bridges, because they mentioned to me – they referred me, and so, I called Spectrum. They told me – they gave me a list of doctors, and I was like, I'll just pick the female doctor. So, it was like, "Oh yeah, because you don't want to deal with a drama queen?" I was like, you got it. She was really good, Dr. Murphy her name was, Carol Murphy – it was pretty cool. She was a really good doctor, and she really cared about her patients – you could tell. So now, the new doctor, I've just seen him once, but we'll see – I'll give him a chance. And he's busy.

BK: Did you start treatment quickly?

P: No, my doctor decided to keep me off as long as I could, as long my numbers were over – as long as I wasn't getting overly, overly sick. Of course, the regular cold, it took me a bit longer to

get over it, but I think I waited five years before medication, because I was still able to work full-time and that stuff. It was pretty cool. And I was getting bloodwork done every three months as well.

BK: You got some support on the healthcare side of things right after your diagnosis. What about elsewhere? Was there other support available to you at the time?

P: Very little. Not as much as there is now. AIDS Vancouver, PWA – Positive Living Society, now, there was that as well – Dr. Peter Centre as well, that was new. That place didn't really – I didn't really feel comfortable there way back, because it was in St. Paul's. On the Thurlow side, there's the parking lot, and I guess it was in one of those buildings there when it first opened, and then they built it across the street. Back then, it was a lot of IV drug users and I didn't do that, so I kind of felt out of place. So, at the time, I didn't feel that was a good support system for myself. I kept with my doctor, and the handful of friends I had at the time, they were good. They were like, okay, it's no big deal, just don't die. It was good. But there will always be stigma, sadly.

BK: Your friends, that was your main support system.

P: Yep, oh yeah. And I told my older brother and sister, and they were okay with it, so they were cool. And my parents still don't know, and I don't think I need to tell them, because I'm not dying, I don't look sick, so they don't... They probably never – maybe I will tell them at some point in my life, but right now it's like if I'm healthy and I can work, why should I? they'll think it's negative, because it was hard enough coming out to them as gay, because being Catholic, you didn't do that, that wasn't accepted back then. But that's a different story, you know, way back then. I have a really good relationship with my parents now, but I live in Vancouver and they live in New Brunswick. I'm healthy, I don't look sick, so there's no need to add extra stress to them and their lives. If something does happen that I do have to tell them, I will, but right now, I have a good support system, I have a good handful of friends, and I have social housing, which is pretty good, so that's pretty helpful too.

BK: It's kind of that idea of your chosen family here.

P: Yeah, you're right. Exactly. It's basically, yeah, that's what it is, chosen family, which is fine because I'm happy, it's good. I'm able to travel, I'm healthy enough so I can travel. I went to Taiwan twice last year – it was really good, it was fun.

BK: That sounds great.

P: I was supposed to meet someone there first, an acquaintance, but I guess two weeks before, they changed their mind, and I'm like, okay, well I have my ticket, I've got my hotel booked, and I don't speak Mandarin, but what the hell? I'm going anyways. I had the best time. It was really cool, a really good experience. And it was actually kind of cool being the minority, because I'm white, especially on their subway, but it was a good experience. I didn't have any problems bringing my ARVs there – they're pretty... Being Canadian, I guess you can travel a lot, but being HIV and Canadian, there's a lot of countries you can't travel to, which is pretty difficult, right?

BK: I think even the United States, there was issues travelling there until like 2008. That's crazy.

P: Oh yeah, they'll always have issues in the US. Sorry, but they will always have issues in the US.

BK: Bringing ARVs across the border was not something you could really do.

P: No kidding. Now that marijuana is legal, that's a whole new different – completely different... But that was pretty stupid when you couldn't even bring your ARVs across the border. It's like, sorry, but you'll need a waiver if you come next time, because you could be banned for life. So, I'm not sure about other Asian countries, but Taiwan was quite open – even London, even England was pretty open. And I like the fact that in London, at the bars, instead of – they have tip jars, but their tips go to charities, which I think is cool. So, they had one tip jar going to an AIDS foundation in London, so I thought that was actually really cool, that's a really good thing to do. So, all my English coins, I kept giving it to them. Sorry if I'm going off track.

BK: No, that's great.

P: Probably going off track here.

BK: No, that's fine. So, did you ever find yourself seeking out support from organizations like AIDS Vancouver or PWA, like you mentioned?

P: Yeah, I've been going to them for a while. They have a good – AIDS Vancouver had good advocates – help with disability applications. They have food banks, which is good, and they also had a fund for like – if some type of medication wasn't covered by MSP, they have a fund that will help people out and cover for their medication. You know, and PWA, or Positive Living Society, they have camp twice a year – you go to Loon Lake. That's pretty cool. They had counsellors, they always had free coffee – it was like another place to be around people just like me. Like, no judgment, no stigma, I'm just understanding, so it was pretty good.

BK: Kind of social support?

P: Yeah, it was social support and I guess another chosen family too in a way, right? Yeah, they did a lot of – they helped me a lot through the years. They were pretty good. And like I said, they were really good with the provincial government, with the disability applications, and they had case workers to help fill it out. But I found also that provincial disability, they were actually – they were not really judgmental as well. For a government agency, that was pretty good, because they knew – they were educated, right? Because they have a university degree, and I'm sure when they were at university, HIV wasn't a subject they took at school, but over the years, they got educated. It was a good thing, because I couldn't work anymore, it was a really good thing to be able to fall back on that. It's good, and I work part-time as well, so it kind of helps out a lot too. So, my community is – there's a lot of support, it's my support system. It's really nice too, because it's nice not to be judged. It's hard enough to be a gay male, honestly – I'm sure you know how that is. My life really improved, you know, because when I first became infected, I

didn't think I was going to – like, five, ten years, you didn't even think about that back then. Like, how long, right? But now, it's like they have that PrEP that guys can take, and even if someone new becomes diagnosed, there's medication. Support systems, they're better now, and medication is much better, so it makes it easier to live every day. In the early '90s, it was pretty crazy.

BK: And then undetectability too, that must be...

P: It's really good, it's pretty good. Although there's still – I still know people, even though I'm undetectable, they still don't want to have sex, and I'm like, fine, go your own way, just go. Get out of here.

BK: You can just hand them the stack of academic literature that says...

P: Go back under the rock you came from, mister.

BK: Because the jury is not out on that one anymore.

P: No, no, no. But I'm much happier now than I was back then in the '90s.

BK: That's great. We talked a little bit about medical responses. You talked about your experience with the healthcare realm. Any reflections on how the government was responding in those early years?

P: It was still kind of iffy, especially federal, because they didn't know how to deal with it. Again, lack of education, even from a government. So, you know, it wasn't as easy from a government perspective, like from a federal government perspective. Provincial government in BC, I know I had a good rapport with. Other provinces in Canada, I'm not sure how they were back then, but with the provincial government here, it was good. Federal government, there was still a lot of unknowns – you know, can you get it from using the same cup or going to the washroom? The mentality was still there, but it's still today, it's still here today, because I had an experience with some guy like that. But you know, over the years, the government, they got a bit more – they realized that you can't get it from sitting in the same room as someone or from sharing the same cup, it's just bodily fluids most likely. But then there was also the tainted blood from the '80s where some people got HIV as well, and that was a different – they got HIV, but they got it differently.

BK: There's a new CBC show about that

P: Yes. Actually, I've been watching that. It's pretty good, but it's pretty sad how some of the people get treated. And then there was that young guy from the States.

BK: Ryan White?

P: Yeah, I think so, because he got it from a surgery, the tainted blood. It's gotten better over the years. There will still be a population that will still choose not to get educated, but it's just like

any other diseases, diabetes or cancer, it's just another medical disease. It's pretty sad that when it first came out, it had to be based on one population of people, right? Now it's a good thing that it's not. Every type of population has the risk of getting it, has a chance of getting it, so no one's really safe unless they know who their partner is, but there still are people who will never say nothing to people who are HIV negative, and it still gives HIV a bad name. It's pretty sad. I think overall, over the years, the government became more relaxed about it, realized unless you're using dirty needles or having unprotected sex with someone who's positive, there's a chance. Now it's like – I'm surprised they still haven't found a cure for cancer, or there could be a cure for cancer, but it's not out yet. Like, now they can cure Hep C, because back then, twenty, thirty years ago, they couldn't cure it, and now it's curable. And hopefully – I don't know if they can ever cure HIV, but it's manageable. People can live a long, healthy life with proper medication. So, I just try to stay where there's support for HIV. There will always be people who are going to be discriminatory toward others, but I stay away from those types of people.

BK: Were you aware of any of the activism that was going on around HIV at that early time as well?

P: Well, the AIDS Walk, and there's the mural they made down by the beach with all the names of people – I thought that was really cool. I don't know if they still – I'm not sure if they go once a year to use it as a memorial, but I thought that was really neat as a way to keep people's memory alive, even though it's gone, even though it's completely rusted. And you know, there was activism back then – more support from the government, but the government was still uneducated. But we've come a long way from way back then. So, I guess the activists are like pioneers to us. I guess they've paved the way. Realized that it's not anything to fear anymore, right? It's sad that a lot of people had to pass away, but I guess I'm just lucky – I'm one of the lucky ones. I don't think about that anymore though – it's kind of cool that I don't think about it anymore. That kind of just brought me a lot down, more down. But to stay with my support system with healthy people. I don't know what else I can mention.

BK: This is great. It's great that if you're healthy and you're only taking one pill a day, you don't have to think about HIV that much, at least not as much as you used to.

P: Yeah, it was pretty tough, you know, because it was something new. And I always thought I'll never get it, yeah, but don't speak too soon. I learned a lot from back when I first became positive to now, and there were struggles like anything else, but people made it through. You became stronger, like emotionally stronger. The support system is still there, which is good, which is very important to have.

BK: How did this change the community as whole, thinking about what the community looked like when you got here and thinking about what the community looks like now? Did HIV play a role in changing the way the community looks in the present?

P: A lot more understanding now. A lot more – the medical field is a lot more educated now, which they provide education to their patients. There are stigmas back then and there's still all these stigmas, even some of the gay, like HIV negative and positive gay guys sometimes wouldn't just interact, so there was still stigma within the gay community itself, which is pretty

sad, back then. It's better now, which I prefer. But everybody was afraid back then as well – it was very fearful, because all people knew was, oh my god, it's a death sentence, once you get it, you'll die. So, a lot of people I knew just kind of wracked up their credit cards, because the doctor was like, you know what, go ahead and wrack them up. [Laughs] And I was like, okay, cool, okay, whatever – oh my god, we're going to die. How many people in Canada don't pay their credit cards off? It was just a few more. [Laughs] It's really improved, it's really made me I guess who I am now, the person I am today.

BK: I think I've asked most of the questions that I was aiming to ask. Do you have any advice for younger folks in the community who might not have experienced this, who didn't live through this?

P: Well, just listen if somebody wants to share their story – just listen to them. There's a lot of education out there now for the younger generation. And if they have a friend that's positive, it doesn't mean anything, it's not going to change who they are, it's just one medical thing, that's all it is. Just like having depression, anxiety. Just keep that support system going, because that's really important. You don't want people to fall through the cracks.

BK: The information is out there, so educate yourselves.

P: Yes please. Even the ones that are in their sixties – come on people. But they're probably just stuck in their old times. Yeah, it's pretty cool. And I think it will just get better as time goes on. Hopefully at some point, the younger generations won't have to be so afraid because – it's like, you can't get it from shaking hands with someone. But I think as the years go by, it will get better for the younger ones.

BK: And PrEP might be part of that too, making people less scared.

P: Yeah, that would be a really good idea to make it – I think it's available in BC. Well, I think it's available everywhere, but some provinces don't cover it. I guess if you have a good medical plan, but I think they should be available to anybody who asks for it, no questions asked. Okay, so they want some PrEP – okay, that's fine. At least they're getting prepared, at least they've educated themselves.

BK: And any advice for folks who might be newly diagnosed?

P: Don't give up hope, it will always get better. Yeah, don't give up. You might want to feel like giving up, but it will always get better, there's always a support system somewhere, a lot more support systems now than back when I was in my twenties. I guess no matter where you live in Canada, there are support systems, so yeah, just accept your friends for who they are. And practice safe sex. [Laughs]

BK: That's a good reminder, especially for younger guys who are coming out into the community now.

P: Yes, raging testosterone – I know that, totally. I was there once, yes. So yeah, practice safe sex – that’s number one, or just self-satisfy yourself – that’s another way as well, which is extremely safe sex.

BK: Well, that’s it for my formal questions. Is there anything that you thought we’d ask about that you wanted to bring up or anything you wanted to expand upon before I stop the recording?

P: Just be there for your friends or family. Just support them, right, because it will make it much easier for the ones who are struggling.

BK: Great, thank you so much.

P: You’re welcome.

BK: I’m just going to stop this.