“HIV in My Day” – Interview 79

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

Ben Klassen: We’re now on the record. Thank you so much for being here, [name], and agreeing to share your story with me today. Just to get started, when did you start getting involved in the gay community or in gay life to some extent?

Participant: Oh, when I ran away from home in March 1969. I was homeless, so I had to put out for a place to stay. But I mean, that’s when I started having sex with men, you know, when I was sixteen years old. Yeah, then I became a prostitute, you know, worked the streets to survive. I didn’t know where to go, right? And back then, you didn’t go to Covenant House, which was a youth shelter, you know what I mean, because it wasn’t gay-friendly at all, and if you went there, you were going to get bashed. And I got bashed so many times back in the ‘80s. I think the street was safer than going there – you know, met up with some friends and stuff like that, connected with people. I was kind of lucky, but I usually ended up back on the street – I don’t know why. I just couldn’t – it wasn’t the rules, you know. Maybe I just didn’t trust anybody. I think still to this day I don’t trust anybody, but yeah, boyfriend after boyfriend. Then I met [partner’s name], and that was 1987, and we had this relationship – we drank, we had an apartment in Toronto, we worked in the brokerage industry as messengers. You know, he worked for [company], I worked for [company], and it was good, you know? And then we used to run home every day and watch the Flintstones – yeah, yeah, yeah, seriously, honest to god. Run home, have lunch, watch the Flintstones, run back to work – well, we were messengers, right? It’s what we did – we ran. So anyways, we drank a lot, we fought a lot, he cheated on me – I cheated on him too, once.

And then I ran away from him, took his wallet – well, first I took his wallet and I stole some money out of his bank machine, and then I bought a one-way bus ticket to Vancouver, and this was 1989, and stayed here for a few months. As far as I’d known, I was HIV negative at that point – it was a normal life, you know? Then I went back to Toronto because a phone conversation, he told me, “[Name], I tested positive for AIDS.” They really called it AIDS back then – no one ever said, “You got HIV?” No, they said, “You got AIDS, man?” Exactly. No, seriously. So, I went back to Toronto and went to Hassle-Free Clinic and got tested, and they said I was HIV. And he said, “Now, do you want to go for a drink now, [name]?” I was like, nah, I didn’t want to go for a drink. It didn’t bother me because I really didn’t understand what this all meant, you know? Yeah. And I watched [partner’s name] decline with HIV, with AIDS, with the Kaposi’s Sarcoma, with Kaposi’s Sarcoma all over his leg, and his leg decaying from gangrene. I saw him die at Casey House, and it was really, really sad, you know? Yeah. But I don’t know. It maybe was the HIV, maybe that’s why I was on the run, you know, after he died – I really was. He died in ’92, so there was a lot that went on from ’89 to ’92, but I did a lot of irrational things my whole life and I think it has a lot to do with HIV, it has a lot to do with what I saw with [name] dying and the look in his face, like I have today.

I remember we used to go out to gay pride day, you know what I mean, Toronto in the early days, and we’d see these guys in wheelchairs, and they had AIDS, back in ’88, you know what I mean, before I had it. And I’d look at them and I’d think, oh my god, I never want to look like that – I'd say I never want to look like that, and perhaps I will look like that someday. He ended up, [name] ended up looking that way. After he died in '92, I had a good job, I was working at [company] in Toronto, but I stole their deposit and ran away with it, and from '92, I ran away to Montreal, and then I went to Halifax, and then I turned myself in once I got back to Toronto in '92 – no, it was '93 I think it was. It was about a year after he died – he died in March '92. '93 I broke the law, ran off with the deposit, ended up in jail for two months. That was so scary – I'd never been to jail in my life, and being HIV positive in jail, they denied you medication, you're labelled, you can't tell anybody you have HIV – they'll beat the crap out of you, they really will. And when they beat the crap out of you, the person who gets the crap beaten out of them is the one who goes to solitary confinement like I did when somebody found out I had HIV on the range. True story. This happened in Owen Sound and I went to five different prisons – they kept on moving me around. They call them buckets, yeah.

So anyways, that's what I did for the longest time with HIV, because of HIV I think, I kept on running, you know? Here, there, Vancouver, Toronto, Toronto to Vancouver, just kept on going back and forth, back and forth – different ways, either by flight or by plane or by hitchhiking. I've settled down now, yeah sure, I have. I've been in my own apartment for seven years on my own, and I've never done that in my life – I've always been with someone else, I had to live in someone else's apartment. I never had my own apartment until now, but that's the greatest regret I have is breaking the law, you know. Yeah, so do you want to ask me a question?

BK: Sure. So, you said that when you were diagnosed you weren't very aware of what that meant.

P: No, I didn't know. I mean, I saw the pictures, I saw the people at gay pride, you know what I mean? And then of course, after I was diagnosed, I saw [partner's name] and that hurt quite a bit – like, I'm feeling it right now, you know? I just don't want that to be my life – you can get injections in the face or something, look beautiful again. Yeah, exactly. But yeah, I was so embarrassed, I didn't want to be with [name] either in public sometimes, I really didn't. He embarrassed me, and I thought, oh, people think I have it. He didn't want people to know he had it. Sexual partners, I had sex with so many people, I never told them I had HIV – I probably infected them. I mean, maybe I'm a killer. You know, I just – it's horrible what I did. I don't know why I did that, but I don't do that now. That was years ago. But I also think I wasn't alone. I think a lot of people were having unsafe sex and not telling people even after they found out they had HIV. They were thinking, well, if this person is willing to do it without a condom, they must have it – that's what a lot of us thought. And even recently when I was sexual, maybe ten years ago or fifteen years ago, I heard that all the time too online, or I'd go to someone's house and they want to have bareback sex, and I'm like, um, well, they're probably HIV positive.

BK: It sounds like you didn't have a lot of access to a lot of information back then.

P: No, not back then. No, not at all. A pamphlet, if a pamphlet – back in '89, no, there wasn't a lot. I remember people telling me, you know, don't get the gay flu – they called it the gay flu. Maybe they call it the gay flu today – that's exactly what we called it back then. Or we called it GRID, but even in 1985 when I first became homeless, and I was only sixteen years old and really, really cute – you know, I wasn't without, let's just put it that way. I didn't have to go without a place to sleep. Exactly. But I don't know. But I once I met [name] in Vancouver, I settled down. I didn't start having all these chronic health problems until about ten years ago, I suppose. That's the hardest part of living with HIV for a long – well, I mean, that's a hard part with living with HIV for a long time, the chronic health issues, and all the do-nothing doctors. I call them do-nothing doctors, because when you've got these chronic health problems, you feel that they're not doing anything to solve the problem. It's just like – like recently, I fractured three ribs in six weeks and that's why I'm at the Dr. Peter Centre right now. And now they're saying, "Well, the pain in your lungs is chronic." I'm like, it's not chronic – fix it. "Your prostatitis, it's chronic. Your heart problem is chronic. Your bowel issues, it's chronic." There's so many doctors I need to go see, and I'm overwhelmed by it. At least I'm not being discriminated by the doctors. They're not saying, oh, we won't see you because you have HIV. That's good – we've come a long way. I'm sure there was a lot of that back then. Personally, it didn't really happen to me, except for that one doctor, Dr. [name] in Toronto back in 2002.

I was pretty lucky, and I was so lucky to meet [name] and live with [name] – it was a good kosher home, and [name] cared about me. I mean, he drank too much, and he made good food because he's Jewish – you know, Jews always eat good food, there's always lots of fruit in the house. It's just a beautiful place, you know what I mean? And I miss [name] today – I don't know where he is, he's not talking to me. He's giving me the silent treatment again. But I'm on my own, and I never gave up my apartment. He always said, "Oh [participant's name], you always give up your apartment for a boyfriend." Well, no boyfriend, no giving up my apartment – I still have my own place. I don't want a boyfriend – no. But I got HIV and I ain't getting rid of it, and this face, which I call an ugly AIDS face – the rejection in this community, you know? But I mean, let me take myself back to 1985 or 1989, '88, when I used to be at gay pride and I'd see these guys in wheelchairs walking around with AIDS faces, you know – what else do you call it, right? Facial wasting. And how I rejected them, and then I feel that rejection today. It's interesting, you know? Yeah, it's happening to me. I don't have the sex I used to have, I don't have people turning their heads on the street like I used to. I feel rejected.

It's been a tough time for me the last few years, last ten years. I've been going to Switzerland many times over – dying, suicide, because I've been so unhappy. And that's why I'm at the Dr. Peter Centre right now, not just because I had problems with my lungs, but also because I have problems with mental health issues, with suicide. So, I'm wanting to fix my problems and I want to be happy. And I don't want to be rejected – I want them to fix my face, I want them to put the fat back in my face. I want to get my teeth fixed – well, teeth fixed, that's easy to do. But the facial wasting issue, I can't just stop taking my meds, you know? And the other issues I have with my health, hopefully they'll get better, and some things are getting better, but you know, the meds are causing this, and I don't know what to do about it. The one thing that I can't do is that I can't stop the rejection of the community – no. I don't blame them. They're all looking for someone young and cute – they are – just like I was. So, maybe I'm supposed to understand all of this. I guess it's fifty-plus, it's long-term survivor – I don't know what you want to call it. It's tough anyways, it's really tough. People say, "Oh, why don't you go to the baths? Why don't you go out and have sex at night time? You look better in the dark." And I do – I go out at night time, people cruise me. I'm like, oh yeah, hot, cool. Go out during the daytime like this, right, they'll look at me from across the street, then once they get a close-up shot of this face, they walk on by. I can tell, you know what I mean, because I've been around for over thirty years, I know the cruise, I know the look. So, it's really tough to deal with this, you know? I don't know. Maybe I can get injections for my face and I'll feel better.

And rejection from the family – so there's rejection from them and then there's rejection from the family. My sister, [name], she hasn't talked to me since 1991 because of HIV, because the day I told her I was gay and then I told her I had AIDS. She said, "Oh please, get out of my life." And then my mother at one point said, "No, you can't come home because of the black flies." This was 1992 – no, yeah, Port Sydney, Ontario, the people in the village of Port Sydney, Ontario had said oh no, you're – they didn't want people with HIV. There was a retreat, I think it was, there was an AIDS retreat in Port Sydney, Ontario, there was, and they shut it down – I don't know what happened there, but I think it had something to do with the people didn't want it there or something, you know what I mean? Yeah, I'm not joking with you, and they came by my house. My mother was kind of on my side, but then she wasn't on my side. Even though she wouldn't sign the petition saying ban all people with HIV in Port Sydney, Ontario – it was in the news – but she did ban me. She said, "[Participant's name], you can't come home." So, I didn't come home for years because of this, because of HIV.

And you know, my childhood and stuff like that, it's not just AIDS or HIV that I'm estranged from my family, it's also because of things that happened in my childhood. I was sexually abused… [18:34-18:53 removed] … So, the estrangement, being estranged from my brothers and sisters, it's because of that, but it's also because of HIV. My brother's a little bit homophobic and AIDS phobic, so he lives in the Sault, Sault Ste. Marie, so we don't talk anymore, and that's all because of HIV and being gay. But he's gay himself, kind of – bi, whatever – he's probably just like me. He has sex underground with men – I don't know what he does. Married with two children. They're all married except for me – I'm the only one that never got married. I hope someday that I can reconnect with my family, but then again, I don't know, part of me just wants to be left alone. I never want to leave my apartment because of how I look, that's for sure. You know, I try not to go too far. Yeah, it's been sad. I'm not joking – this is a true story. So, I'm going to look in to see if I can get the fat put back in my face. It's not that bad, no, but there is a little bit of facial wasting in the face.

BK: I was going to say it's not that bad.

P: Yeah, I know, I know, I know. People always say that, but I look in the mirror and I don't like it, you know? And I've been taking opiates for pain for like eleven years now, and that causes aging as well, right? I mean, I always looked ten years younger than I was. When I was twenty – well, let's say when I was twenty, I looked like I was fourteen years old. Imagine what I looked like when I was sixteen years old. I must have looked eleven or twelve, okay, and I did. And when I was thirty, I looked really young too. But then I had this boyfriend from 2002 to 2003, only a year, but he swept me off my feet, [name], a Mexican refugee, and I fell totally in love with him. He was like my best friend… yeah, he was my best friend, and he died in 2007. But anyways, we had an apartment together, and I was a rollerblader – learned how to rollerblade after I met Kurt Browning, and that's how I started rollerblading. And people would be like, this guy, look at him go, right? Yeah, seriously. [Laughs] I used to be that way. You know, and then I got into the crystal meth and the gay orgies, and the online orgies – well, I didn't have sex online, but I met them online. And I got into the crystal meth, and first I was a weekend warrior, and then I was an everyday warrior, and then I was so sketched out, nobody wanted me. Then I became a buggy boy, you know, and finally quit on my own.

When I started going to the Dr. Peter Centre in September – oh, the reason I did the crystal meth is because I broke up with [partner's name] in January of 2004, and when I broke up with him, it broke my heart, it broke my life, broke my will. I didn't even want to skate anymore, and that was the hardest thing, because that's all I did was skate, either on the ice or on the street, I rode my bike all the time. I still smoked and whatnot, you know what I mean. Yeah, I was always on the go, I was pretty happy. But you know, when you break up with someone, it can be – he had HIV too. We're not going to get into his discrimination, but he felt a lot of discrimination himself, but in Mexico. He came to Canada to get away from that discrimination. He came here to save his life and ended up dying. Yeah, it's pretty sad, eh? But I'm still here. I'm still here, I'm still standing. Not the pretty boy I used to be, but I'm still standing. Yeah, and you know what, I haven't used crystal meth since February 23, 2007. I mean, I used to smoke pot up until February 4th, but I still smoke cigarettes, but I don't smoke pot anymore because I fractured those ribs, and it's so painful when you fracture the ribs. Like, I couldn't sleep, I could only sleep sitting up if I wanted to sleep, so I needed a hospital bed in January of this year, February of this year, so then I got into the Dr. Peter Centre. [Name] got me in, another [name], the worker over there, he got – there's so many of them – he got me into the Dr. Peter Centre immediately, within two days he got me a bed. Nobody gets a bed within two days – lightning speed. Because I was in tears with the pain, I've never felt so much pain.

There's a lot of things I can be proud of – not using crystal meth for twelve years, not using crystal meth after [partner's name] died, you know, because I used it after we broke up, but I didn't go back to it when he died. He's probably looking down from heaven and very proud of [me]. I'm not going around giving people HIV by having unprotected sex. I have a lot to be happy about. I should think about those positive things, all the good things I do for myself and for others, you know, and get back on those skates, because it made me very happy. I've still got my rollerblades at home, so while I'm at Dr. Peter Centre, they painted my apartment, they cleaned my carpets – they did everything. My place is going to look like Hollywood when I get home. No, it will, seriously. I'm going to go live there happily ever after, I guess – I don't know. I'm going to join a Wednesday group over at Dr. Peter Centre – I don't know if you've heard about it. It's for long-term survivors and they come there, and they socialize with other people. I need to get out of my bubble. I need to socialize with people my age. I've always gotten along with people who are older than me, usually Jewish old ladies – no, it's true, since I was a little boy. And [name] was Jewish too – well, he is Jewish. I don't know, I think he's still alive – god, I hope so. He won't answer my text messages and that's kind of bizarre, because we didn't have a fight or anything, and there's no reason – on my birthday, he didn't even answer my text message, but he never remembered my birthday anyways – drinks too much sake. Anyways, I'm going to be okay.

BK: Living with HIV for thirty years is no small feat either.

P: No, it's not.

BK: That's not something that your doctor would have said was even possible at the time.

P: No, no, no. My mother didn't ever expect that I would be living past the year 2000, you know, and I never expected it either. And the future scares me – you know, it just scares me, especially if it's anything like the last ten years, then I don't know if I want to be here. If it's like the ten years, I don't – it's been a tough ten years, it really has. The heart attack, the pneumonias, the fractured ribs, broken bones, broken heart – yeah, for sure, absolutely. I don't know what to do. Join the Wednesday group, seek counselling – I have to. I have to figure out what all these long-term survivors, how they cope, you know? There must be a support group for long-term survivors. I'm sure there is over at St. Paul's. Everyone always says join a support group, join a support group. I'm like, oh, yeah, yeah, yeah – that's me, right? Yeah, I'm going to do it, yeah, I'm going to do it. Yeah, I'm going to go to smoking cessation. Yeah, I'm going to do this – procrastinate, right? Stop procrastinating and start doing shit. Like the dentist, someone has to drag me to the dentist like a little puppy to the vet – they do. And chaperone me to the healthy heart program so that I can get rid of some of this cholesterol that's choking my heart, and that's due to long-term surviving, for sure. I'm thinking, why did I have a heart attack when I was forty-two years old? That's young. Why do I have so many bouts of pneumonia even though I've been vaccinated with pneumovax? That's due to being a long-term survivor. The longer we live, it seems the sicker we are sometimes. More likely you're going to have to battle cancer, cardiovascular disease, arthritic pain – lots of pain.

That's the toughest part, to go to the doctor and to have them believe and hear you and believe that you're in pain, or when you need to go to emergency, such as when I fractured the ribs in February, go to the emergency department and not be believed. They said, "Oh, your pain is being caused by COPD, there's no fractures." And then later on, the senior radiologist looks at the x-rays and says he has fractured ribs – okay, fractured ribs and two tumours within the right lung that's causing problems, and now they have to do a biopsy within my right lung as well. I've found a lot of times, they don't believe me, but I don't lie – I don't think long-term survivors lie, and I often wonder are they having problems like me? Or they don't want to give you pain medication – I don't know if that's connected to being a long-term survivor, but maybe, because the longer you live, the more issues you're probably going to have, and you might need pain medication or anxiety medication – both. Nowadays, "No, we can't give you both. We can't give you the anxiety medication as we did before and the pain medication as we did before because of the opioid crisis," you know? I was thinking, what? "Oh, you might get dementia." I'm thinking, get dementia? I'm not worried about getting dementia, I'm just worried about living for the next five years – five to ten years, really. I think they think I'm going to live for twenty-five years more, and I don't think so. I think it will be lucky if I'm here ten more years. Well, maybe if I start rollerblading, I could live a little longer, but I don't see a long future ahead of me.

But I think in the next little while things are going to – things have gotten better, but I'm overwhelmed by too many things that I need to do. And the Dr. Peter Centre hopefully will help me. They help long-term survivors. The respite care that I'm in is helping me a lot. Thank god we have that here in Vancouver. A lot of long-term survivors have checked in there for ninety days, trying to regroup and get it together, because you need it. It's really tough being a long-term survivor. It's overwhelming, like I said, it drains you – it just totally sucks the life out of you with all these what I call do-nothing doctors, because everything is chronic, right? Oh, there's a pain in my testicle. "Oh, that's chronic too." Just get out of here. You know, fix it, you know what I mean, and then it won't be chronic anymore. I think they just say it's chronic because they want me to keep coming back, because if I keep coming back to their office, they can keep billing MSP – sometimes I think that. I don't know – I'm sure that's not the case but…

BK: It feels that way.

P: It feels that way, yeah, it does actually. I think things are little bit better than they were. And after a while, you just give up and you just go, [sighs], well what am I going to do? This is the life. Maybe it's not as good of a life as you have, but it's a life, right? We've all got our problems, I suppose. Like, I remember when – oh, I remember, I would take my medications for all these years. Back in the '90s, I would never take my medications – I'd take it one day, I wouldn't take it the next, so I developed a lot of resistance to those medications. And then when I was taking my medications, I'd stop taking my medications, and then I'd feel – I'd go out the next day, I remember walking up the street at Yonge and Eglinton in Toronto thinking, "Oh, how I feel so normal today. Not on HIV meds – I feel like a normal person today." I did, and I'm telling you the truth, that's exactly what I was saying to myself. I was looking up at the sky thinking I'm going to go to the employment office today, and now we're going to go get ourselves a job, and we're not going to be on disability anymore – yeah, seriously. Didn't last for long. I had to go back on my meds. Yeah, so much for being normal. That's how I felt. And I still feel that way today, kind of. And I'm not stopping my medications, because I can't.

[Partner's name] used to say to me, way back when, while he was still alive from '88 to '92, '89 to '92, when he knew he had AIDS and I knew I had HIV, [name] used to always tell me, "[Participant's name], you have the benefit of time." And I suppose he's right. He knew something that I didn't know, seriously, and he used to always say, "[Participant's name], it will be your lungs that's going to be the problem in your life." Look at the problem that I'm having with my lungs and my heart. I don't like being alone, but it is what it is. They want to send me back to that apartment, and I'm saying no, no, I don't want to go back there, I don't want to be alone. I mean, yeah, I can get up in the morning, go to the Dr. Peter Centre, use the day health program, go here, go there, and then at the end of the day, I have to go back and be by myself again. All of my life I was with someone. If it wasn't for love, it was for sex, for whatever, but it was for something. Now I'm all by myself. I don't know if it's because I have HIV – probably part of it for sure, right? And I have to go back to that place that I've lived for seven years. I don't know, the older you get, I think that's just the way it is, you find yourself alone. Senior citizens probably live alone, and I'm only fifty years old and I'm living alone. I'm not a senior but maybe for HIV, maybe the HIV makes you a senior before you're a senior, you know? HIV is going to give you cancer before you should be getting cancer – premature. Like you said, premature aging, premature cancer, premature loneliness, premature suicidal thoughts. You know, it's happening to me. So, I don't know, just make it through today. Ask me anything you want to ask.

BK: Was there any support available to you back in the '90s?

P: Back in the '90s, any support?

BK: Or recently after your diagnosis?

P: There were counsellors at AIDS Committee of Toronto, and there were counsellors here in Vancouver as well. No, there wasn't a lot of support, I don't think. And I didn't find [name] very supportive either when I met [name] May 31st, '95 – he wasn't really that supportive, because we would go out together to Friends for Life. I'm not sure if you've heard of Friends for Life before, but in the early days when Lorne Mayencourt and all of them started Friends for Life in the condominium on Beach Avenue before they bought that house and renovated it – I remember the condo, right? I've been around that long. And [name] used to go, "All you people do is sit around and talk about your illnesses and stuff like that," but this is the person who I would live with for the next fifteen, twenty years kind of thing, you know what I mean? And that's the way he was. It wasn't very supportive – couldn't talk about what was ailing me, about being chronically ill, couldn't really talk about that kind of stuff. I never cried in front of him – when I broke up with [partner's name], I was always in tears, but I would never ever cry in front of [friend's name] because I knew that it was just a waste of time. I didn't want him to see me that way, I never wanted him to see me cry. You know what, he never did see me cry. Yeah, exactly. But no, there wasn't a lot of support.

BK: Was Friends for Life supportive at the time for you? Was that a place that you felt cared for?

P: I think there was counsellors – yeah, you know what, there was quite a lot of support at Friends for Life, and then at BCPWA. I met people there that were supportive. I ended up started volunteering there in the late '90s over at BCPWA, and that was supportive in itself – made friends, you know? Met [partner's name] there – that's where I met [name]. He was volunteering writing for their magazine in Spanish, and yeah. So, those were the supports, I suppose, but in the early days, no, I don't think there was as much support – there wasn't. There was a lot of fear, you know what I mean, but though there was a lot of fear, there was still a lot of really risky behaviours – oh yeah. Because everybody thought, oh, this couldn't happen to me – I hope I said that loud enough – but no, they did believe that. And so did I – I thought, oh, that's not going to happen to me.

BK: So, why wear condoms or why worry about that?

P: Yeah, exactly. Why worry about that, because it wouldn't have an immediate… Yeah. I guess that was a mistake. Sometimes I didn't have the option of saying no – I was being paid for sex. It was in me before I even woke up. [Laughs] Sorry I'm laughing. It does happen.

BK: That's a different kind of power dynamic too, right?

P: Well, I know, exactly. But I'm not there today, that's the positive thing. I pulled myself out of that crap. Now I have to deal with this loneliness, feeling of loneliness, you know, the aging issue, premature aging. Yeah, because sometimes I look in the mirror and I see this young boy and I hear this young boy, this beautiful boy, but then I turn the lights on or take a picture of myself, and I'm like, ah! What the fuck happened? Yeah, my ugly AIDS face. Well, that's how I see it, and I think that's how a lot of other people see it too. Maybe not you – you're not going to say it to my face. Walk down the street – they don't lie. I probably would have had sex in the last ten years – I don't know the last time I had sex. Fuck, it was so long ago, and the only reason why I haven't had sex is because of the rejection, it's not because I haven't wanted to have sex. I'm horny all the time – well, not right now, but all the time – I'm not going to admit that too right now. No, I'm serious, right? Rejection. And I don't know. I've got to get some help with this. They're referring me to psychiatry – I don't know if that's going to make a difference, because I don't think she understands what I'm going through. She's not a gay man living with HIV with facial wasting. Only that person probably can understand how I'm feeling, someone who's been rejected themselves by their community. Once I was number one, now I'm number none – that's how I feel, and it's sad, it really is.

BK: We can wrap up pretty quickly if you want. I think we've covered a lot of the questions that I wanted to ask.

P: I guess most of the rejection I've felt in my life either came from my family or it came from my community.

BK: And that's horrible.

P: It is, it is. Because since I was a child, twelve years old, somebody wanted me for sex, right? [44:26-44:38 removed] So, you know, I mean, it was always somebody, and now all of a sudden, you start looking like you've got AIDS, and nobody wants me. Yeah, it's hard to deal with. And I don't want my family to see me this way either, that's why I won't call them, that's why I won't send them a picture of myself. Dr. Peter Centre does not have a picture of me that's current, I don't want them to have a picture of what I look like today – I don't anybody to have a picture of this face, except for BC ID for my ID, identification – I have no choice with that, right? Oh yeah, you were going to do the video recording and I said absolutely not. You probably should have though.

BK: Well, it's completely optional.

P: You probably should have because then they would see a picture of my face and they'd say, oh yeah, that's an ugly AIDS face, or they'd say, ah, what is he going on about?

BK: I think that's what a lot of people would think, to be honest, but that's just my opinion.

P: Okay. Well, it's what I think that matters. It really does, it really is.

BK: Of course, yes. And how you I feel.

P: If I say that this is happening, the rejection, then it probably is happening, you know? I don't know. Or maybe I just don't want to repeat the behaviour of the past by rejecting them and not having unprotected sex, not having any sex. Sometimes that's the case, but most often it's them rejecting me.

BK: As we kind of get near the end here, what advice do have as a long-term survivor for folks who are newly diagnosed?

P: God… Take your medication, don't miss your doses – you'll create resistance and it will make it worse for them, especially if they have to take more medications to control the HIV. More medications with bad side effects such as diarrhea or facial wasting like I have, you know? I don't know what the other side effects are – neuropathy, let's not forget that one with the tingling in the hands and feet, pain in the hands and feet. Those horrible side effects, but they don't want to look like me, they don't want to have an AIDS face, because then they'll be rejected too. So, just take your medication, don't miss your doses, don't create resistance to your medication, and you'll live a long, long time. And just enjoy your life.

BK: What kinds of programs were there at BCPWA back in the '90s?

P: God… I don't know. Just, they had a lounge there – I know that. They had the lounge, which we were able to smoke in – a lot of people smoke, right? HIV can be very stressful. They had that, the lounge, and I volunteered in the lounge, but they also had the Loon Lake retreats, so that was a program as well. They had used clothing, Polly & Esther's, this thing there. They had advocacy – they would advocate for their clients. They had a little internet café. I can't quite remember what other programs they had. Most of the counselling – and they had a CHF fund, complimentary health fund, which they would reimburse people for their vitamins and their water and whatnot, their receipts every month up to a certain of money. But it was the counselling and whatnot, it was more AIDS Vancouver than BCPWA, right? And then we had Friends for Life and they had counsellors as well, and they had massage therapy, so there were programs. And Dr. Peter Centre was here, but it was in the hospital at the time, back in the '90s, remember? And they had programming too, but they were limited in how many clients they could serve, and I tried to get in there, but they told me that I didn't qualify because I didn't have a significant amount of drug use or mental health issues. So, once I started using the crystal meth, then they let me in. I didn't use the crystal meth to get into Dr. Peter Centre, but they let me in after I used the crystal meth, and it was the best thing that could happen to me, you know? That's when I started stopping using meth.

Maybe the meth was the drug, the mother of all drugs for me in my life. Maybe it's a good thing I used it, because it was like, okay – and the heart attack, that happened for a reason too. The doctors at St. Paul's hospital said, "Listen, if you snort one more line of crystal meth or if you snort one more line of coke, you'll have a major heart attack and die." So, after that, he told me that, I said, oh, I can't do that. I've seen meth pipes, I've seen people snorting meth and coke, I've been at parties where it was there, and I've said no to it and I've been successfully able not to use it, for sure. But other programs – some programs but probably more today, especially at the Dr. Peter Centre. There were always counsellors. Maybe there's more counselling today than there was before, maybe there's more support groups out there. I never really accessed that kind of counselling, that's why I had a reckless life, because I didn't seek counselling. Maybe I can't really answer all of that. Think about it. I saw a couple counsellors in Toronto in the early days, that's it. I just kind of tried to live life like I was normal and didn't have it. That's why I didn't take my meds, that's why I went out and had all kinds of sex, and didn't care if I gave it to others, you know? I didn't, but I do today. So, what else?

BK: Were you aware of any aspects of AIDS activism that were going on at that time? Was that something that you saw going on?

P: AIDS activism. I saw it on the news, like ACT UP and stuff like that. I remember back in ’84, ’85, this is before the ‘90s, I remember them screaming and saying, “Stop calling this a gay disease.” That was about it. I didn’t participate in the activism, I didn’t participate in those protests – I didn’t think it was really my life, you know what I mean? Remember, I saw the guys in the wheelchairs with the AIDS faces and the Kaposi’s Sarcoma all over their face, and I was like, oh, those poor people, you know what I mean? I had empathy for them, I realized they were part of my community at the time, but I never wanted to be there. I’m sure [partner’s name] thought the same thing, and then he ended up there. Hopefully I won’t end up there, in a wheelchair with KS, you know. Pump some fat in my face and be normal again – I just want to be normal again. Maybe I’ll never be normal again – maybe I never was normal, maybe there’s no such thing as normal, you know? We’re all different, and if anybody’s going to love me, they’re not going to love my face, they’re going to love what’s inside of me and who I am, period. I keep trying to tell myself that – I think that gets me through the rough times. I think so. You know, just looking at myself and saying, “You’re beautiful, [name]. You’re one of the most beautiful people you know, or maybe I am the most beautiful person I know.” I know I have a good heart. That’s not what they’re attracted to though, they’re attracted to your face. Your face is your signature and [pats stomach] that too. You don’t have to worry about that – you’re skinny. It’s not about you anyways.

BK: It’s definitely not about me.

P: It’s about my rejection, not about your rejection. I get it, I know.

BK: Has your perspective on HIV changed? When you were diagnosed, it was probably like a death sentence, or thought about as such. Has your perspective on HIV changed in any way looking toward the present?

P: Well, I think that I’m going to live longer than they said I was going to live, that’s for sure. Has my perspective on it changed? Yeah, I suppose so. When I tested positive, I just thought, oh, big deal, I have it. Remember, I didn’t go for that drink, right? It didn’t freak me out, I didn’t run away right away, it was only after [name] died that I started running away and breaking the law – well, I broke the law once, only once. I think if it wasn’t for [name] dying at Casey House, I wouldn’t have broken the law, so HIV/AIDS played a big role in me breaking the law, me having HIV/AIDS played a big role in me breaking the law and using. I often wonder if I never had HIV – if I never had HIV, would I not have all these chronic health problems that I have today, you know? And I think the answer might be, and it would be, no, you wouldn’t. I’d be normal like my brother, or normal like you, normal like the next guy on the street, the bus driver, the doctor, the nurse – just normal like all of those people out there. A not-so-normal person. Maybe if I can get back on my rollerblades, I can be that normal guy again. Or maybe I can be that normal guy again and still take my medications – can I feel up here in my brain normal? Take your meds, rollerblade, and tell myself, “I’m normal. A normal long-term survivor.” That’s what I need to do. Yeah, I need help with that, I need to get there, I need to build a bridge.

Someone help me build that bridge. Stop going to Switzerland. I'm not going to Switzerland. Okay, next.

BK: I think we've really covered pretty much everything that I would have asked about. You covered a lot of it in just telling your story.

P: Well, you can just edit it. I know, I just babble on. I told you.

BK: No, that's what we want. We want to hear your story.

P: Back and forth too, and I'm sorry about the back and forth, but it's my ADD brain.

BK: No, don't worry. We do always like to end by asking if there's anything you want to add or anything that you thought we'd ask about that we haven't asked about that you wanted to share in thinking about your journey with HIV.

P: No, I think that's it.

BK: Then I'll just say thank you, again.

P: You're welcome. It's been a pleasure. It was tear-jerking at times, thinking about certain people – well, people, not about events. [Partner's name], that kind of bothered me to talk about that, for sure, not because he was my boyfriend, because I felt like he was my best friend. A short-lived relationship – his life was short-lived, but at least I knew him. We had our time together. We were friends for as long as – and you know what, he was the only boyfriend I ever had that I took home to meet my mom, it's true.

BK: Which would have been a very big moment in your life, I'm sure.

P: It was, it was. I don't know. I should go home and visit my mother someday. She's normal. She's not normal, that's the thing. I ran away from something I thought that wasn't normal, you know, running away to something that might be normal. I don't want to run away again, because there's nowhere to run to. I'm too old, too old to run, that's how I look at it, you know? Run to counselling, run to a support group, run to go get new wheels for my rollerblades – it's nice out now. I'm thinking, oh, I could have a massive heart attack rollerblading – I said, you know what, who cares? Dying doing – even if that happened, I would die doing something I love, and that's how people remember me.

BK: Well, it looks like a good day for it today.

P: Yeah, I know. I need to get my rollerblades tuned-up – the bearings need to be cleaned. Can you rollerblade?

BK: I used to rollerblade a lot, actually.

P: It's so much fun, and you feel so free.

BK: It’s fun.

P: I remember rollerblading to Dundas all the way up to the east end, and I’d get a call on my cellphone, it would be [name], he’d say, “Come on over, I want to see you.” And I’d rollerblade so fast with my headphones on – I’d be like, oh yeah, you know what I mean? I was so excited to go be visiting him. Yeah, it was like that, it’s the kind of relationship we had – I ran to him. And he’s not the reason why I quit rollerblading, it was the heart, you know? It was the cholesterol and the heart probably, so I really need to go to healthy heart first and go through that program before I can get back on those skates, because if I go directly to the skates, something bad could happen. So, they have to drag me to healthy heart, cardiac rehab. There’s lots of rehab that has to be done – long-term survivor.

BK: I think it’s really good for us to capture the fact that long-term survivors have all these ongoing health needs – concerns and things that they need addressed – because I think a lot of the time those things aren’t being addressed in the way that they need to be.

P: And how they affect us, you know what I mean? For sure. Done.

BK: We’ll stop this.