

**“HIV in My Day” – Victoria Interview 3**

**December 13, 2018**

**Interviewee: Michael Yoder (MY); Interviewer: Art Holbrook (AH); Also present: Ben Klassen (BK)**

**Art Holbrook:** So, what is your connection to Victoria?

**Michael Yoder:** I grew up in Victoria. We moved here—I was born in California, and when my father died, my mother’s parents lived in Victoria, so she was Canadian, she moved us up to Victoria. And uh, we lived here ever since, like 1969.

**AH:** Just as an aside, are you--do you have any problems with US taxes, given that you were born in the US?

**MY:** No, I never worked in the states. I was nine years old.

**AH:** It wasn’t about work, it was about whether you were born there.

**MY:** Ah well, they’ve never, they’ve—

**AH:** Had the right of citizenship.

**MY:** No, I renounced my citizenship.

**AH:** Oh, you did.

**MY:** Yeah, I naturalized as a Canadian. So—

**AH:** Oh, okay. Uhm, so, now having that out of the way. What did Victoria look like before the HIV epidemic?

**MY:** A lot smaller. It was um, always been sort of a conservative government town, it’s always had that feel to it because it is a government town. But in the sort of remembering back to my teenage years it was very... much more homophobic, very little diversity as far as the colours of people... so a very white town. Parts of it, like where I’m living now in Esquimalt, that municipality was always a very big Navy town, so, there was a kind of a culture of Navy and government and a mix of those things. Much shorter, much less density, so more houses, more theatres than there are now. Now that all that’s coming down, we’re getting more condos. So, it was that kind of a feel but...

**AH:** Yeah, well, I noticed that moving back here after being away for four years, that it was getting more and more dense. So... when did you first hear about HIV?

**MY:** We had – well back in the... I guess it would be early, early ‘80s, we had very little outside of the club. So, it was kinda like the gay scene in Victoria was the Queen’s Head, which was like the dance club out in Esquimalt. And there wasn’t anything much else for guys to connect other

than over alcohol, so a bunch of us got together and said, well, why don't we do something like – we called it the Gay Café. So, it was just like a – it was in James Bay, in the community school there, and they had a little cafeteria area where we'd just have coffee and some donuts and whatever, and guys would just be able to get together and talk, but not with alcohol involved. So, it was that kind of a refreshing thing. And then, there was one guy who was kind of the first guy in Victoria, [name]. And he suddenly, he came in one day and he was like, "I've got it." And we kind of knew what he meant, but that was kinda the first exposure to it, and it was that shock of like, oh God. And that was kind of my first experience of hearing about it. I mean I heard about it through the news, but it was kind of a Los Angeles, San Francisco, far away, New York, kinda thing. It wasn't here.

**AH:** Right. Yeah. So, what was your sense of how bad it was when you heard about that?

**MY:** Um, well, yeesh. We knew it was bad in big cities, but in Victoria there was always this kind of, funny island – it was an island mentality, like, well, it's not going to come over here, because that's in Vancouver, that's over there. As if nobody ever leaves here or nobody ever comes here, it's like we're shut off. So, initially there were only, like after [name], then we'd hear about like one or two other people, so it seemed really kind of like, okay, it's here but we didn't even know like how guys were getting it. It was just – it was just this – people were getting sick, but we didn't know why they were getting sick. So, it didn't seem like a major, major problem in Victoria.

**AH:** So, what—put a date on that, what kind of timeframe are we looking at?

**MY:** Oh, 1980, '81, around there? '82, when it just started creeping in and more news coming out of big cities. But not a lot going on here.

**AH:** Was there any news coverage of it here?

**MY:** Only about, in those days, only about other cities. Very – not anything much talked about in Victoria, that I'm remembering back, that's a long time to remember back. But I don't think there was anything much in the news, other than what was going on in Los Angeles.

**AH:** So, you say that you didn't know how it was transmitted, so how did you learn more about it? What sort of...

**MY:** Well, okay, in the sort – '83, '84, '85 it started to become more clear that, yeah, it's being sexually transmitted. And then there was more information started coming from Vancouver, because AIDS Vancouver had started up, they were putting out more brochures, trying to get the word out. Some of the guys from Vancouver were coming to Victoria just to give little talks on like, safe sex, and not sharing body fluids. That was the big thing—no sharing of body fluids. And even kissing. Like, at that time, it was nothing – don't share anything.

**AH:** There must've been a lot of rumours around along with the good information. What kind of stuff was passing around at that point?

**MY:** Oh, well, there was still the whole, all the fears around toilet seats and telephones and sharing, like don't share dishes, or cutlery or anything. So, a lot of misinformation was still floating around.

**AH:** And did you find yourself passing on the good information to other people?

**MY:** I was very young and not really involved yet, so I did some talking to people. Like a few of us would talk together about what we knew, but was I that conscious of it, was I that involved? No, I wasn't. I was only twenty-two, twenty-three. I was infected when I was twenty-three. I wasn't diagnosed until '95, but I was mostly likely infected in – when I was twenty-three, which would've been '84. Because the big thing back then for a lot of guys in Victoria—me included—was you'd go to Vancouver to have a naughty weekend, 'cause that was just the thing to do, go to Vancouver and have a naughty weekend. And there was one particular experience... where I got fucked and afterwards, I just thought, there was something different. Something was wrong. I just – something just came into my head, that something was wrong about that. And it wasn't long, too long after that, that I ended up getting, having a seroconversion illness. And I had a lymphadenopathy so my doctor said, "Well, could be AIDS." We didn't have HIV back then, we had AIDS. But she said, "Let's just..." I said, "Well..." She said, "Do you want to get tested?" 'cause I think by then they were getting closer, I think they had the test back then. But there wasn't a cure or anything, so I thought, okay no, I don't want to get tested, I'm just going to live my life. The thing then was, what we talked about, and that was a piece of information that I think I did pass on to a lot of guys, was assume that you're infected, assume that your partner's infected, and just play accordingly, play safe.

**AH:** Well that partly gets into the next part of the question of how did you respond to it personally? Anything else you want to add there—did your behaviour then change?

**MY:** Yeah, I know then I was really – we had more information about where to get condoms, and how to use condoms, the whole condom culture was big, in the sort of mid '80s. Well, mid '80s right even through to like, 1997. So yeah, I was much more aware of what I was doing sexually with partners.

**AH:** But did it change your sexual habits?

**MY:** Um, I was twenty—I was in my twenties, I had a libido then, so no, it didn't change my sexual habits. I was still out there being a randy twenty-year old or twenty-six-year old or whatever.

**AH:** Just that you had condoms in your pocket.

**MY:** Yeah, just that I was going to use condoms if we were going to engage in anal sex. Not so much with oral sex, and that was one of those things where a lot of guys chose like right from the beginning we're not going to use condoms during oral sex. I tried it once, and frankly, it's like having a balloon shoved down your throat. It's not a pleasant experience. So, most guys even with oral sex just said, eh. And it was shown later that oral sex is really a low-risk activity.

**AH:** Yeah, I can just—

**MY:** Sorry, I'm getting pretty graphic here.

**AH:** No, that's fine. I think that's pretty important information about what was going on at the time. Did you use alcohol or drugs or any of that sort of thing in those days?

**MY:** I never did use drugs and I drank at the clubs and stuff, but not to any great excess.

**AH:** So, it wasn't a – you didn't get into a alcohol-driven party scene?

**MY:** No, no... I mean, a few times I'd get really, really drunk, and I think once or twice it was like what did I do last night, but, that didn't happen very often. So, no. And I know, I mean I would never drink to the point that I didn't know what I was doing, or I would let my guard down around sex. So, I always had that in my head, like I was always really clear about that.

**AH:** How did your, or did your identity change, or your thoughts about yourself as a gay person change when the epidemic came along?

**MY:** It didn't. I've never been... I mean, once I came out of the closet, I came out of the closet, I was out. So, I wasn't going to be... Mind you, in a conservative little town, it can be dangerous to be out. Even, like, Victoria, even though Victoria's bigger than like Nanaimo or Trail, BC or something it was still... there were bashings going on, and I remember one night I was down at one of the cruising spots and I got chased by a bunch of bikers, who were essentially like, you know, pounding their fists – they were trying to scare me, and they did. So, I just went to the first place I could. There was a Denny's on Douglas Street and I thought, people and lights, people and lights. I went and sat at like – well, I don't know, it was almost midnight, and I went in and sat there for an hour and a half drinking coffee, 'cause I didn't want to leave, just in case.

**AH:** But uh, did AIDS or HIV alter your identity in any other way?

**MY:** I think I became more... because as time went on and more and more guys were getting sick. Like, more and more guys were getting sick. So, one year I remember, I don't know, there was probably about ten or twelve guys in a year, and they're all in their like thirties and early forties so, it was always younger people. And we would hear about suicides, there were a lot of suicides. So yeah, I think it made me, it made me more compassionate towards what was going on for people. And over time I've had the benefit of living as a negative person, as an unknown status person, and then finally as like a known status person, and I got to watch how people behaved to other people and treated other people. And sometimes it was shocking. Like, I know I had a friend once who, I had several friends who were saying "Well, you should get tested, you should get tested." And I said, "Well, I don't want to get tested. There's no cure." And by this time, we had AZT too, which was killing people, as far as I'm concerned. Because it was like massive, massive doses every four hours, and guys had their little timers that would wake them up every four hours, all the way through the night, to take these massive doses of this dangerous chemical. There was this pressure to get tested, and I was saying no, and this one guy just said, "Well you're in denial then." And I thought, what, do I want to join your club? I'm sorry, it's

like is it really that important to you that everybody be tested and we all know? I would fall apart if I was positive. So, I think it actually, my skepticism around everything over the years has actually served me quite well.

**AH:** That's interesting. And did the epidemic alter your relationships with people, or with the community?

**MY:** Well, finally, I was in university for a year, and then after that I started doing some advocacy work, just as a volunteer. And then I think I heard about even more guys getting sick, and this is like 1986, '87, and that's when I got involved with AIDS Vancouver Island on the helpline. We had a helpline. And that was kind of my introduction to like, let's get involved, now it's my turn to do something about this. So, I volunteered on the helpline, and eventually I'd start helping with like training people to be on the helpline, and I was the first volunteer coordinator at AIDS Vancouver Island back in '87, '88, somewhere in there. And burnt out really quick 'cause I was too young and didn't know what I was doing. Yeah, it changed me that way, like I thought, no, I need to do my part now, I need to do something.

**AH:** How about in your individual relationships, as opposed to your community?

**MY:** Not in my individual – I mean, I was single anyway so I didn't have a partner back then. I got together with my partner in '89 or '88 – can't remember that one but somewhere in there. And he got tested through pressure from a friend. And... he fell apart. He was an alcoholic and he went on a seven-day bender, seven-day binge, just because, and I kept thinking, don't do this, it's not going to be a good idea. It's like, you know, you're a healthy guy right now, you're not dealing with any major issues. And he did and I watched that, and I thought I'm really not getting tested, 'cause I don't want to fall apart like this.

**AH:** So, shifting gears a little bit, what kind of response did you get from the government, or from the medical community, in the early days?

**MY:** Well, the government didn't want to touch it, not with a ten-foot pole, so and I think it was Vander Zalm at the time and he – they ended up giving money to AIDS Vancouver, and AIDS Vancouver Island, and a few little other groups, so that they could do the work because they didn't want to touch it. They didn't want to talk about it. And the whole thing during the eighties and early nineties was, you know, it's just a bunch of gay men anyway, so who cares? And the government kind of had that response. But they also knew, we have to do something, so we'll hand it over to community groups, and then they can use words like “fuck” and “suck” 'cause we can't use those words. The medical community we had... I think we had two or three specialists back then, so there was some, good response from the medical community, but at the same time, there was always a huge amount of fear. And they were always gown, glove, mask, 'cause you know, even if they knew, you were gay, never mind that you were positive, but just being gay they wanted to gown, glove, and mask just in case. And that was the days when, I mean, well, early, early '80s to late '80s I think was when I would see stories on the news of where they're wearing, doctors are going in in space suits, because they just don't want to risk the chance of like, well, what if it's in the air, or what if it's... I mean they just, people would... So, the medical community was like some people were really compassionate and other people were just

like, total jerks about it, and didn't want to learn, didn't want to know, just wanted to stay away from it.

**AH:** So, can you amplify what that jerk behaviour was?

**MY:** Well, on some levels, especially with gay partners, gay partners were not allowed to go visit their partner in the hospital. They were barred from hospital, only family, and your gay partner was not considered family, so they couldn't come in. The gowning, gloving, and masking when it really wasn't necessary. It wasn't until Princess Diana came along and actually didn't do any of that, that people started going, oh, I guess it's not that bad, I guess I'm not going to get it. But it took people like her to kind of wake people up to like, you know, you're not going to die just by visiting somebody in a... And that was in the days when people were still getting a lot of Kaposi's sarcoma, so there was a lot of facial disfigurement. And the illnesses were a lot more severe, and less treatable, than they are today.

**AH:** So, there was a lot more visible things to be afraid of?

**MY:** Yes, I think that was... And I think that a lot of the fear even today, for a lot of guys, around, 'cause like there's still a lot of gay guys that don't have a clue about HIV. They don't have a clue about it. They don't know what undetectable means, they don't know any of that stuff, and their fear I think is rooted in the '80s. I think the fear for most people who have any kind of fear around HIV is rooted in that past, where it was such a scary thing, and people were disfigured and people were dying, and you know, the images of people in hospitable beds all shrunk and wasting away. So, I think that fear affected not only people in the gay community, but also the medical community. Because that's where it's like, well, I don't want to get this, because I don't want to be like this person.

**AH:** Well, they called it "slim" in Africa, because people got very slim. What was – you talked a little bit about the medical community's reaction. What was the public reaction?

**MY:** Same kind of stigma. I mean there was a joke that I heard somebody say it once, and it was just like what the fuck. "What does GAY stand for? Got AIDS Yet?" That was kind of the – it was like the 4-H club which was you know, homos, hookers, Haitians, and hemophiliacs. So, we are all kind of lumped in with this – well, we were like toss out people. It was like, who cares about them anyway?

**AH:** Well, I remember the joke about, it's hard to come home and convince your parents that you're a Haitian.

**MY:** Yeah, exactly.

**AH:** So, did you personally experience any of this kind of behaviour?

**MY:** No, I just experienced... Well, I experienced generalized homophobia, like being yelled at on the street, name-calling, that kind of thing. But never anything really physical, and never anything, but just people being insensitive around jokes about gays and jokes about AIDS. And it

hurt. It was like, I am a throwaway person, or you think of me as a throwaway person. I don't think I internalized any of that, but I probably did, actually I probably did, because I think everyone has internalized homophobia. Everybody has it. And it's kind of insidious, because you don't really recognize it's there until something comes out of your mouth and you're like, "Oh, that was homophobic, and that was about me. Where did that come from?" So, but other than that, just generalized homophobia from people.

**AH:** And did any of this kind of mainstream behaviour, did that affect your perception of the epidemic?

**MY:** Maybe it's what actually drove me to do something in the end. It actually made me angry enough just to say, you know what, I've got to do something, I can't just sit back anymore. I'm watching all these people that I've cared about die, and I'm watching a general community that doesn't give a shit. So, I want to do something. So, I think maybe that sparked some impetus in me to actually go out and...

**AH:** So, what did you do?

**MY:** Get on a helpline. I got on a helpline. And back then, it was like, I mean, we had the information, but essentially, it's like here's the book, here's the phone, when it rings, answer questions. It was like, very little training in the early, early days. But that's when we had, you know, the computers were black with orange type and it took four hours for them to start up in the beginning of the day. So, we had just very basic, basic training on some active listening and that was about it. And probing questions so that you could try and figure out what's actually going on for the person on the phone.

**AH:** What about other people around you who became involved in responding to the epidemic?

**MY:** I'm not quite sure what that means.

**AH:** The question says, did you or your caregivers, family, loved ones, become involved in HIV communities or start engaging in responses to HIV/AIDS?

**MY:** Oh, okay, well here's the story of VARCS: Victoria AIDS Respite Care Society, which is not there anymore. But in the late '80s, early '90s, my partner – it was even after he was diagnosed I think. He took training as a home support worker, so he was going, and he asked specifically to work with people with AIDS, because none of the other home support workers wanted to go into those houses. They just didn't, they would refuse, so he was right there to say "I want to go in." And what he started noticing was that a lot of the people who were sick, their family was burning out, and they'd end up in hospital or hospice a lot sooner than they needed to be, and it was simply because the family's burning out, because caregiving is twenty-four hours a day, seven days a week. And you don't get a break, you don't get to rest. So, his idea was, why can't the community become extended family? Because he remembered his family, where if somebody got sick, then all the aunts and uncles and cousins would come by and make sure like okay, is Auntie, does she need us to cook for her or clean for her, so she doesn't have to do anything, so she can just spend time with her sick husband, or whatever. And I think the first

meeting – how many people were there? Twenty or thirty people at the first meeting. So, the community, he brought together, it was really interesting that he brought together all these people.

And the idea was to set up respite homes where the person who was ill could actually go and stay for a few days, in one of these houses, so that the caregiver could actually just take some time for themselves and not worry and not have to work. And it was really very successful, because in the early – that would've been in the early '90s – it really got going, there was lots and lots of – I mean, that was almost the peak of it for Victoria. So, the homes were always busy. I mean not always busy, but they were busy. Usually they'd have – one or two them had people at least two or three times a year for anywhere from a couple days to a week. And the challenge was, in some cases the person would be sick enough that they'd actually turn palliative in the respite home. So, suddenly it's like, they can't be moved now. There's no bed in hospice, because hospice is tiny. So, we'd just simply set up home support for the volunteers in the house, and make sure the nurses were coming in, and the palliative response team was coming in. And the person would actually be dying at the volunteer's home, which was never our intention. But it happened. 'Cause things could change on a dime—a person could seem fine, and then within a day they'd suddenly be dying. So, it was really a successful little program, little society that I think helped raise awareness in the medical community, because Gary sort of insisted that HIV and AIDS be part a of the – there was like a palliative resource team, and he insisted on being there. And just saying you have to deal with this, you can't ignore this. So, it raised the awareness for palliative people, as well as for nurses and doctors that, no, this has to be looked at. This can't be ignored anymore. So, he did a lot of work that way.

**AH:** And didn't he go to Ottawa, and deal with this with Health Canada?

**MY:** I think he did! I'm trying to remember back, all that way too. He did a lot of different – like, he would go to conferences and he was involved with – I think he went to a CAHR [Canadian Association for HIV Research] conference once, I don't know how involved with Health Canada—

**AH:** CAHR?

**MY:** Uhhhh... CAHR.

**AH:** Canadian AIDS Resources...

**MY:** I think so, and there's also a palliative nurses, or nurses who work in palliative care, and he went to one of their conferences. I think he did talk to people in Health Canada. There was a doctor at Health Canada that he was fairly close to, later on, when we did Positively Fit. It was all part of a – it was the second phase of an evaluation, because VARCS was the first group, I think in Canada, to say, evaluate what we do. Give us some money, we want a formal evaluation conducted by university people, looking at what we do, to see how effective we are. And if we're not effective we'll go away. And it proved that, yes, we were effective.



**AH:** Well, somewhere in there, I came in. I regard Gary as a hero. I really do. He really did something. So, you were talking here about the next question, with any aspects of AIDS activism. What was your role with VARCS or with the other organizations?

**MY:** Well, at the beginning, I got to sit around the kitchen table at eleven o'clock at night and listen to it all day long. It was like living and breathing VARCS for Gary and since he would come home and it was like, well today I did da-da-da-da and I did this and that and I think we should do this, and we should do that... And I was like I just want to go to bed now, I'm tired. But yeah, I think... um, sorry what was the question? I've lost it now.

**AH:** What was it...

**MY:** What was my role?

**AH:** Yeah, what was your role with VARCS or the other organizations?

**MY:** Well, at AIDS Vancouver Island, it was sort of helpline and then doing volunteer training, and at VARCS one of the things that we did to actually help offset some of our costs was to train home support workers who weren't getting any education in AIDS and HIV. So, I helped organize those, and we'd bring in different speakers to cover different topics, and I on occasion would present something myself. But it was a lot of bringing in speakers from other agencies to talk about their experience with HIV. And the home support workers invariably all said they really loved having that training, because it helped calm them down and make them feel more comfortable about being around a person with HIV.

**AH:** You've really dealt with the next question of how the community dealt with this intense burden of care. You've spoken directly to that. But how do you deal with the accumulated grief of people dying?

**MY:** I still, ah..... [Sobs] It's hard. It's hard. Um... As much as you know I—I—I'm still involved in the work at PWA here, every once in awhile something will happen... like a song, a song will play, and I'll cry for two hours, because it all comes flooding back... and I think, that's something the general community doesn't have that experience, of like, how can you lose so many people from your community and not feel that, and not have that? And we did a talk about accumulated grief—and yes I will have a Kleenex thanks, or two or three—um, we had a woman from hospice come and talk about accumulated grief and she said, “Really it's something you don't ever get over, grief. You just kind of live with it, it's in the background.” And for me, I just know it's – yeah, it comes back up, and not all the time, it's not consistent and it's not always bubbling under the surface, but something will trigger it. And then everything's flooding back. All the people. Like World AIDS Day. World AIDS Day on Facebook, I posted something about World AIDS Day and I said, “Today I remember...” and I started listing all the people, and as the day went on I remembered more names, and I'd keep adding to the list. And I would remember them. And for a long time... I mean, one thing that really, really struck me about accumulated grief was I was in Ottawa, I was on the Canadian AIDS Society Board of Directors, and one year they decided to show part of the quilt – the Canadian AIDS Quilt. And people were reading names as the quilts were being unfolded, and I was sitting right—I apparently scared

Alan Rock, who was the health minister at the time—I was sitting right behind him, and they read off the name of [name], and I lost it, because I forgot. I forgot. [Sobs] And I realized like how—how—how simple and easy it is to forget as time goes on. You forget. And then something—but then, it’s like I said, something will happen and it will trigger it and bring it all right back. And that, that one, I mean I literally started, I couldn’t stop weeping, and I made Alan Rock sort of jump in his seat. Which apparently was quite moving for him, but at the same time wasn’t so great for me, because then a couple people later and I had to go up and read names while I’m sobbing. But yeah, that’s really how it’s affected me. It’s not gone away.

**AH:** Nor should it. Thank you for that. How have your perspectives on HIV and prevention changed over time?

**MY:** Oh, we have so much more information now. I mean, in the early days it was don’t share any body fluids at all, and then finally they dropped kissing off the list, and then oral sex was sort of not so bad even if you swallowed cum or whatever. And now we know so much more with the “U equals U,” undetectable is untransmissible, all that kind of stuff. We have so much more information about how the medications, the improved medications since ‘96, make it much, much more difficult for people to contract HIV. But we’re still seeing new infections, and that’s the scary part, we’re still seeing new infections. We’ve been seeing here ten new infections per quarter, which is a lot – that’s forty in a year. That’s a lot of new infections when we had been down to maybe eight in a year. We’re going back up, so somewhere along the line, people aren’t getting the message.

**AH:** I want to go back a little bit – ‘96, ‘7.

**MY:** Yeah.

**AH:** What happened that triggered Positively Fit and what about Positively Fit?

**MY:** Well, it came after the evaluation... I can’t remember where Gary came up with the idea for it, but there was sort of this kind of an idea of like, does exercise help the immune system? So, we came up with this – he came up with this program where we got some free passes to the Y, and different rec centres, and people could go and work out, but then the deal was you and get your bloodwork taken like, more regularly, just to see, like, what happens. And it turns out in the end that, no, exercise actually didn’t have a big impact on people that way, except that they felt better. And I – that’s I think the most important part, was that people felt, as long as they felt better. It’s like therapeutic touch, I’ve done therapeutic touch and it’s like, people claim it does all kinds of things to your immune system, and changes this and blah, blah, blah. Well, I can’t prove any of that, but I know people get relaxed, and if you’re relaxed then your blood pressure goes down, blood pressure goes down, you’re more calm, things ease. And it’s the same with exercise, it gets your blood flowing, it gets you moving, you feel more supple, you might have more energy. For skinny people like me, when I was working out at Positively Fit, I was eating, I think I was the heaviest I’ve ever weighed, I was about a hundred and forty pounds, because I’ve always been skinny. So, I think it really helped people understand that their bodies were important vessels and that they could work on their bodies and they would feel better. And also it brought out people who had never been to any AIDS group before. That was one of the big

things – there were people who had never accessed anything, and they suddenly started coming out to this and got involved, and some of them are still involved at like PWA Society or AIDS Vancouver Island. So, it's really benefitted the community that way too.

**AH:** I guess we don't need to go into the politics of what happened with that one.

**MY:** No, we don't.

**AH:** Leave that one alone.

**MY:** There's politics in everything. AIDS is one of the – what do they say about the AIDS movement? The AIDS movement eats its young.

**AH:** Well, it certainly did in that case. With the new drugs that have come along, when Positively Fit came along it was when the first anti-retrovirals were, I think that was...

**MY:** Well, the first—it was when the cocktail came out, about ninety-six, yeah, was when the cocktail was released and announced in Vancouver. And those drugs, what's interesting on medications, because we're all kind of test subjects – they know in the short term what the medications will do, but they don't know in the long term what the medications will do. And I have lipoatrophy now, from D4T, which is off the market now because it causes lipoatrophy. They figured that out over time. If you take too much of a drug, like people were ending up with diabetes, people were getting the buffalo hump, Crix's belly they called it from Crixivan, because you get fat redistributions. People getting fatty liver. And that's still common. So, they know short-term this is what these meds do, but over like, in ten years of taking it what will it do? They don't know that.

**AH:** Well, what's my excuse? I don't take Crixivan.

**MY:** Don't make me go there.

**AH:** Exactly. So, have these, have they got to the end of AIDS?

**MY:** Hmmm?

**AH:** With these drugs, the new drugs that have come along that have been effective, do you have the...?

**MY:** Oh, the end of AIDS.

**AH:** Have they signalled an end of AIDS?

**MY:** No... it's just chemotherapy. Stop the chemotherapy and everything comes back. I went on a drug holiday, 'cause for a little while – when was that? Late '90s, early 2000s, drug holidays were popular, were all the rage. "We're gonna put you on a drug holiday. We think you're doing fine." But the minute I went on the drug holiday, well my viral load started rising and my T-cells

started dropping, and so then it's like, oh, put me back on this and I am not going off it again. 'Cause that had happened to everybody. Literally everybody who went on a drug holiday. Just suddenly see the viral load start rising. And then the risk is if you go on the drug holiday then that wipes out a class of drugs for you, because now the virus has mutated around those meds and they won't be functional anymore.

**AH:** Scary stuff. Do you have any advice for health professionals about what's happening now?

**MY:** Ugh. I think health professionals have come a long way, but there's still a lot of... there's a lot of homophobia, still a lot of homophobia, still a lot of AIDS-phobia. Like, they don't know, they're not learning, we're not teaching it as much. And I don't think the nursing courses will teach about HIV, but it's like uh, this tiny little bit of a chunk of what they learn. And I'm not suggesting that they need to do, you know four months' worth on HIV, but I think they need to learn more about HIV and understand it. And I also think learning about relationships between people is really important. Especially in the health professions, nurses are better than doctors, although my last, my GP was really great. I mean when I was diagnosed, she actually cried more than me, which was wonderful to see in her, 'cause she's a compassionate woman. But um, I know that some specialists, essentially, they just look at your bloodwork, they don't ask about what's going on in the rest of your life. So, there's no holistic aspect to how do we treat people, at least in Victoria. I know in Vancouver things are different. Like there's Spectrum Health Clinic, there's Oak Tree for women, and you get see a social worker, and a counsellor, and a doctor, and your specialist, and all that stuff happens under one roof. We don't have that here.

**AH:** Well, if it's any consolation, all specialists are dicks no matter what you are. I've had the same.

**MY:** It's the joke – what's the difference between God and a doctor? God doesn't think he's a doctor.

**AH:** Yes.

**MY:** So yeah, no, my advice... One, I don't give advice. I'm gonna suggest, I might make suggestions, but I think learning, just learning and talking to people as people. And I think it's getting better that way, but we're still a ways away from a workable health system.

**AH:** Well it must've been the days when Gary was going into talk to some of these people in the courses, and other people I'm sure did the same, that personal contact, here is a real gay person with HIV talking to us, and he's a human being. That must've been good for nurses who were coming into the profession, for example.

**MY:** Oh, I think it was incredibly invaluable. I was doing talks – I haven't done one for a long time, but I was doing talks fairly regularly with the massage school. And mostly it was – they want to know about transmission, prevention, and that kind of stuff. And then at the end I would tell my story about my experience with the healthcare system, and just say like, you guys are caregivers but you're also human beings. And the person you're working with is a human being, and HIV is a tiny little part of their life. I mean we have likes and dislikes and fears and hopes

and dreams just like everybody else. We don't constantly think—I don't constantly dwell on like oh I'm going to die. There's too much crap online and Facebook to visit, I'll focus on all that, not focus on dying.

**AH:** What about any suggestions to the political world? As opposed to the medical world.

**MY:** Well, they've come a fair way too. I think one thing would be good would be to go back and acknowledge what they didn't do in the '80s, what governments did not do in the '80s that really devastated communities. Like Australia, to their credit, they poured money into AIDS, they poured money in, and their infection rates were incredibly low because they were that much more advanced about it. And Canada didn't want to do it. Not even the Liberals, not the Liberals or the Conservatives, whoever was in power, they just didn't really want to touch it. They did finally, they did set up like, Health Canada had their sort of AIDS, I can't remember what it was called then, it's PHAC now, but that's a more general thing. They had an area that was specific to HIV. The province came along in the '80s, so they did start doing something, but they weren't kicking a lot of money into supporting community agencies so that we could do the work, 'cause government doesn't know how to do that. They don't know how to work with people. No government knows how to work with people. So, I think for them, they need to really learn how to work with people. And not just to pretend.

**AH:** Surely there must be individuals in there.

**MY:** Well, oh no, there are, and I don't want to make that blanket too. There are individuals that are really good, that are incredibly compassionate, wonderful, they're politicians but they're also people too. And they recognize that the people in their constituencies are people, and they care about them, and they do a lot of work to support them. But I think as a system, as a system, it needs to become a little bit more understanding of the plight of people.

**AH:** How far has – I mean government has certainly changed. You've got people like Randall Garrison, who's openly gay, in parliament now. How far has government come?

**MY:** Well, we have – I mean we have gay marriage now, and we have openly gay members in pretty much all parties, I think, all parties have openly gay members. So, it's come a long way that way because, oh, twenty years ago I'll say, maybe even less than that, they wouldn't have been able to be open. You can be open in the military now. And in fact, we had one of those first kiss things when the ship came in was two guys got, I mean a guy was kissing his lover and it was front page in the paper. Which I mean is like one of those – is it good or should it just be not a big deal? Currently, it's still a big deal because it's a big deal. When you've got politicians down south who are pulling away, pulling away rights for gays, rights for trans people, pulling away HIV research money and putting it somewhere else or just getting rid of it. It is still a big deal.

**AH:** Yeah. Thinking back on all this period of time, is there anything that you would've done personally, done differently?

**MY:** I think I would've gotten involved earlier. I think I would've gotten more involved with – well, community agencies were just starting up in Victoria, but I would've, I think... been doing the work a lot earlier than when I started, if I think about it. What else would I do? I don't know... it's kind of hard to think back to when you're twenty and you're kind of self-absorbed. You're kind of in your own little bubble with your friends and going to the club. I mean, that was the thing, go to the club and drink until two o'clock in the morning, then go have something to eat and then get to bed at four o'clock, wake up at nine and do it all over again. That's the twenties, that's your twenties. And I wasn't – I suppose I was an activist in a way, but I suppose more in the gay community than anything to do with HIV. But I was always about how can we bring more support in the gay community for men and women, for gay men and lesbian. We didn't have the alphabet soup back then—it was the 'LGB', wasn't even a 'T' yet. So yeah, I think I was always – I think I kind of did my bit, you know? I wanted to see people come together in places where it was a healthy environment, as opposed to just drinking.

**AH:** How much credit can the actions—the ACT UPs—and all the rest of the actions of the gay community take for responses that we have now?

**MY:** Oh huge, huge, huge. ACT UP, I mean, even in the '80s, there was work going on in Vancouver, and activism in Vancouver and across the country where people were like just essentially saying, "Give us the meds. You're not giving us any meds. We need something." And the AZT was terrible, terrible, terrible, and I think most people will say that now, looking back. But at least they pressured the government into doing something. I remember being at the first Canadian AIDS Society Annual General Meeting where we burned Jake Epp in effigy, who was the health minister at the time, and we stopped traffic in downtown Toronto. And it was exciting. So, there was a lot of activism going on that pushed governments to really, really do something. And not just say, we're going to ignore the problem and just make it go away. We were butt-kicking back then. I'm too tired to butt-kick anymore. It's like butt-kicking is for young people, I think.

**AH:** How has that kind of thing played out? I mean the acceptance of gay people, the activism on other diseases, like breast cancer and so on.

**MY:** Well, I think the HIV movement learned from the gay movement, the gay movement learned from civil rights movement, so there's always been these movements that have taught the next movement, so I think, it's this progression through time of the next group will learn from the previous group. They'll do it in their own way, they'll do their own thing and they'll have their own focus, but they've learned from other people's work. And it really started with Martin Luther King – I mean, ultimately it started with the civil rights movement in the States. That's what really kicked off the women's movement, and although—I'm going to go back even further than that actually. No, maybe I'll take that back—the suffragettes. The suffragettes were the first ones to say, "No, we don't like this. Change it." And it changed.

**AH:** You're leaving out the abolitionists.

**MY:** Well, then the abolitionists! They weren't as much, they weren't actually maybe in the streets. I don't know maybe they were in the streets.

**AH:** Not as much.

**MY:** Yeah, 'cause you could take it back to the French Revolution, and that didn't end up well for everyone.

**AH:** Well, and the American Revolution.

**MY:** Yeah, I know. There's always been revolutions and I think now, we haven't seen a big revolution like the American Revolution or the French Revolution, but I think the revolutions we see now are around specific issues, like climate change or like HIV or like guns – gun issues in the States where the students are rising up now, so we're seeing more. And I think it takes those young people to actually do that. It's like you guys, you're the ones who have got to start making the change, 'cause us old people, yeah, we're around but we've already done our own bit in our own way with other movements.

**AH:** That's good. Is there anything else that we haven't covered here that you want to say?

**MY:** I don't think I can think of anything else.

**AH:** Stop prying into my life?

**MY:** [Laughs] Yeah, stop prying into my life. I wear briefs, not boxers.

**AH:** Okay, now we're getting down to it. [Laughs]

**MY:** No, that's great, thanks.