“HIV in My Day” – Victoria Interview 13

February 25, 2019
Interviewee: Claude Gamache (CG); Interviewer: Art Holbrook (AH)

Art Holbrook: First of all, just introduce yourself and where you’re from.

Claude Gamache: Okay, my name is—pardon me, I’ve got a cold so I’ll sound a little scratchy—my name’s Claude Gamache. I’m from Alberta but moved to the West Coast in the early eighties and—do you want to know my history a little bit or how much do you want?

AH: Oh, just quickly, yeah.

CG: Okay. I nursed, psychiatric nurse at St. Paul’s in Vancouver from mid-eighties till the early nineties. After I was diagnosed from HIV and I started getting sick, I went on long-term disability. Was very involved in the poz support group in Vancouver, then moved to Salt Spring Island in the early nineties and formed, co-founder of the HIV Gulf Islands support group there, that still exists. Then moved to Victoria, and I’ve been here since 2001. And I’ve been Board Chair of VPWAS here, and have done a lot of work with AVI as well. I’m a patient at Cool-Aid and yeah. I’m, yeah, that’s about it for my…

AH: Okay, some of this stuff will come back up as we go through questions here. So, you were a psychiatric nurse at St. Paul’s, so you must’ve learned of HIV pretty early. So, when did you first hear about it?

CG: Uhm, in the early eighties when I was working in Vancouver, before I got the nursing job at the hospital, I started hearing—I was living in the West End, in Vancouver—I started hearing that there was some kind of gay cancer going around and they didn’t quite diagnose it yet, and uh, I was singing with the Vancouver Men’s Chorus—it was a gay men’s chorus—and uh, you know, word started getting around that there was something going on in the gay community in the early eighties. And weren’t sure quite what it was yet, at that point.

AH: So, you knew about it but –

CG: I knew about it—

AH: --you knew of it but not about it.

CG: Yep, knew about it. And then by 1982, ‘83, some guys were starting to get sick and it was quite evident, especially with the Kaposi sarcoma that was evident in the – in those years. Especially in the West End, you could see things quite drastic, that were quite evident when you saw guys walking down the street that were not well, that were sick. And by the time I was starting to nurse in ‘86 at St. Paul’s Hospital, it was evident that, yeah, the AIDS pandemic had started, and we were starting to see patients. Yeah.

AH: So, you learned about it, but how did you learn about it?

CG: I learned about when I got—I learned more about it when I got diagnosed, in 19-—in the fall of 1985. In October of '85, I was diagnosed with HIV, through my doctor. And didn't start on any meds or anything yet, just started monitoring my bloodwork at that point, and hoping for the best. In those years, they told you you might have just two years to live and at that point members of the group where I was singing, with the Vancouver Men's Chorus, were starting to get sick as well. And had our first person die actually, about in – I think in 1988 in the group and yeah, so… I started getting more informed after my diagnosis. The Persons with AIDS Society in Vancouver had really formed, beautifully their first support group in BC was in Vancouver, and we organized and supported each other. There's a beautiful man called Ken Mann who worked as a support leader there. I'll remember him well. He died in '95 before the medications came out. But he was very instrumental in bringing people into that group, and we saw the first woman—Peggy Frank was the first woman that came into our group in '86. And that was a lifeline for us at that point.

AH: Did you find yourself educating other people about it?

CG: Oh, absolutely, but the problem with that too in those early years, they still didn't know how it could be transmitted. So, you know, if you were admitted to hospital and you were HIV, they put you in quarantine. And you know it's like, they didn't know if you could be contacted through saliva, if you kissed somebody or if you touched somebody even. People were, you know, were compared to like the early – what is it that early plague that was so prevalent?

AH: Bubonic plague?

CG: Yeah, or the, you know, lepers – like nobody wanted to touch you. And that's very much the way it was until in the late eighties when they finally said, yeah, you can't get it through kissing. But it was like, it was pretty drastic in those early years to be, nobody—yeah, to be so stigmatized with that at that point. And there's graffiti starting to go up in the West End in those early years, too, about, you know, yeah, queers got what they deserve and that kind of stuff. It was going all over the West End. So, it was a really hard time in those early years.

AH: So how did you personally respond to the fact that you were HIV positive?

CG: It was hard because I – it was the diagnosis that you didn't know what—you know the doctor said, "Well, it could, you could get AIDS quickly, you know, we don't know." But they were saying at that time, it's like, give 'em two years to live you know. So, it's like you started thinking, okay, well, it could—it could—the onslaught could happen that fast.

AH: Did you practice safe sex? Did your sex life change?

CG: Uh, well sex life for me didn't exist after that. You know it's like it—used to go to the bathhouses in the early eighties and seventies. It was prevalent to go to the bathhouse if you were a gay man. That's how we met each other. But no, after being diagnosed, it's like certainly didn't want to go to the bathhouse and start infecting anybody else. So—and in those years, we didn't know what safe sex was until later on, when they said you couldn't contract HIV through kissing or through body fluids so it's like—in the early years like we were, didn't know how you could—that's why people were so paranoid and so stigmatized because we didn't know how the transmission was—guidelines were.

AH: So how did your identity shape your experience of the epidemic? I mean, you're a gay man, so that's a big part of that.

CG: I think it definitely affected the gay community in Vancouver, where I was at, at that point. And because I extended myself by being in a gay men's chorus as well, so that affected me even more because it was talked about, and we did fundraisers. So, my identity as a gay man didn't change other than I knew where to go to get help. And the gay organizations helped that. And I'm very proud that we have that kind of history that we—because it was so hard to get any recognition from government at that point—I don't know if you've heard of the organization ACT UP, but I was a member of that group who started protesting in front of parliament, in front of doctor's offices, you know, or Members of Parliament, just to make them aware of what we were going through. And at that point, there was no funding, there was nothing going on, so it was like we had to be on the front lines through our PWA, yeah. So, I'm very proud that we did that, but it was tough. But we organized and we organized quite well. Yeah.

AH: So how did the epidemic manifest itself in your personal life, in your personal relationships. Did you have long-term relationships, and how did that work?

CG: Yeah, I'll start with my family, I guess. I think for me it was difficult—I come from French Canadian background, I've got two brothers and four sisters—so it was hard to come out to my family. And to some extent, some of it went okay and some not so okay. It was a difficult time. My father had passed away by then, but it was a hard time to open up to my family about that.

AH: So different family members responded differently?

CG: Yeah, and it was a hard time to just connect with them about that. And I found very soon into the pandemic that my family soon became those with HIV. That's where I could get most support and feeling of family. So that happened quite early on, in the mid-eighties. I found that my support was not so much blood family, but family that I found through—and there was a lot of women too in the HIV positive community, a lot of lesbians who really helped out. A lot of people in the gay community really came out and supported us as well. But it was hard. And the relationships I've had during that time, I had a few relationships and it was hard. I had—I was madly in love with a guy for about three years and we went travelling together, but our sex was really difficult 'cause he was not poz. In those years, too, it's like you didn't know if you'd let somebody suck you off or you know, would have oral sex with you or have any sex with you because at that point the lines weren't really drawn in the sand about where the transmission occurred or how it could occur. So those relation-—I had a few relationships in the eighties that were really tough that way where, yeah, how much touch could you be? My partner always wanted to have a condom on so I couldn't even give him oral sex. So, that was a hard relationship. And I had a few of those, and it was much easier to have just sex with another HIV positive guy, you know? And didn't have to be a committed relationship, but you know, on occasion, when you got together with a group of guys at a party or something and you knew somebody was HIV positive and you wanted to have sex, that was fine. Because you felt okay, you felt like you were safe.

AH: So, when did things get a little more definite about transmission?

CG: I think by the late-eighties, yeah, I think they had ruled out—because, I mean, I was psych nursing at St. Paul's at that point, so we were starting to see guys with HIV and AIDS that came in our psych ward with—who were HIV positive and who wanted to kill themselves. Because a lot of people were going through a lot of rejection from their family and even their mates, their partners. So, we were seeing a lot of that, and yeah, it was a difficult time to see how that was affecting guys who were HIV positive, not only health-wise, but mentally as well, and the stigma that really started to affect guys, pretty intensely. And it was affecting me quite a bit too.

AH: So how—we'll come back to your professional life there—but uh, personally, once you did know more about transmission, how did that affect your life?

CG: I think – it was interesting, it's like back in ninety—when I finally was getting so sick I couldn't work anymore and I took long term disability, I moved to Salt Spring Island. It was interesting because none of the doctors there—there's a hospital on Salt Spring. It was like we—I met another woman, Peggy Frank, who's well-known in the gay community, and a long-term survivor as well, that I met in '85, '86 in Vancouver, and she lived on Salt Spring as well. And we ended up getting together—and I met another woman on Salt Spring who was straight, who was also HIV positive, [name]—and we started Gulf Islands AIDS Society, that still exists today. But we became the advocates for trying to teach the doctors on Salt Spring about HIV. So, we were the ones doing all the research, we knew what was going on, while the doctors had no clue, or they knew minimal amount. And being on the front lines and seeing specialists in Vancouver—because we had to go back to Vancouver living on Salt Spring to see our specialists who are HIV—we became the ones teaching the doctors about HIV and what it meant, and how we could stay. It wasn't until '96 that the medications came out so we were just going back to Vancouver and getting all the information, doing everything we could just to stay alive. And so that's how we supported each other, through alternative therapies in the early nineties especially, late eighties.

AH: Did you use AZT?

CG: Nope, that was never offered to us, because it was just the one drug that was offered in those early years, and it didn't last long because it was like it was found to be a drug that was killing more people than it was actually helping. So, it was never offered to me through my doctor, so I was one of the fortunate ones where, you know, I was able to survive up until the time we started getting medications in '96.

AH: Tell me more about your professional life. You were a nurse in the psychiatric at St. Paul's,. How did the AIDS epidemic manifest itself there? You must've dealt with quite a lot of people dealing with end of life issues and so on.

CG: Absolutely. Thank you. It was an interesting time to be a nurse, for sure, and a psychiatric nurse on top of that. I think for me, the psych ward was in a separate area of the hospital, so it was very much not the same type of atmosphere as a clinically – a hospital where we're dealing with mostly medical issues. We're definitely dealing with medical issues was mostly, we dealt specifically with eating disorders and people with pain disorders, but we also took people with severe mental disorders as well. And we started seeing guys come in who were severely depressed because of their HIV, and were threatening to take their own life. That was becoming quite an issue on our unit, and seeing more of that. But also, seeing the people that were admitted in the acute psychiatric unit who were – who were HIV and were showing up at the emergency who were HIV positive and were, yeah, not knowing how to—

AH: Freaking out?

CG: Freaking out and not knowing how to take care of themselves. And what are they going to do now and so—the acute unit, on occasion we were asked to go and sit with guys who were coming in—mostly guys—who were coming in and yeah, feeling distraught and suicidal, because of that diagnosis at that point. So, it was affecting it. And then people were still getting quarantined in the late eighties, you know. They're still coming into the hospital, feeling even more stigmatized because nobody could walk into their room without gowns and gloves and a mask and severe restrictions at the door, you couldn't just walk into that guy's room. So, in those years, no one wanted to touch you as well. So, there's a huge amount of stigma going on at that point still. A lot of stigma and a lot of—that was hard to deal with in those years. That was harsh.

AH: So how did you deal with it? You were dealing with this constantly. There must've been—

CG: I think I was dealing with it—I mean my life, I was fortunate. I mean, singing with the Vancouver Men's Chorus definitely had an outlet for me to voice that, and I've been a singer all my life, I'm still singing today. I sing in a group as we speak and I drum – I drum with First Nations right now. I've been drumming with a group called the Unity Drummers for going on three years now. And the Indigenous community's been hit hard with AIDS as well, so I've been fortunate as Board Chair on numerous occasions to work with First Nations people that have been suffering with HIV, and I drum with those people. I sing in groups with people, with the gay men's chorus in Vancouver. So, I had outlets. And the support group, and the poz, and what they offered—you know they offered retreats for HIV positive people at Loon Lake, and that was a godsend to be able to go out for a couple days at Loon Lake in the late eighties for me, and nineties—to be with other HIV positive people and feel relaxed and okay to be yourself and be surrounded by people that had the same diagnosis with you. That was a godsend. To be able to be with that, to be with those people.

AH: To be without judgement.

CG: Without judgment, don't feel stigmatized, and, there's some beautiful people from the Persons with AIDS Society in Vancouver that were just phenomenal, and here as well in Victoria, that supported us, yeah.

AH: So, when did you move to Victoria?

CG: Uh, after I started my meds in – when I lived on Salt Spring, I started trying meds, and then my meds weren't working, so I ended up seeing Dr. Montaner—he's a very famous AIDS doctor in Vancouver—saved my life. And I moved to Vancouver shortly after I started a big cocktail that he put me on to—I had full-blown AIDS by the late nineties 'cause my blood count was down to zip. My red count. And by the time I moved to Salt Spring I had been seeing Dr. Montaner in Vancouver, I think I was on about eight different HIV meds by that point. And I was pretty ravaged with it in my body and it was affecting me in so many different ways. And so, I was connected with Cool-Aid here and there was a doctor Chris Fraser here at Cool-Aid that I got seen, he's an HIV specialist here. And Chris pretty much saved my life. I was able to finally trickle down from a Montaner cocktail of eight meds to about four, and then with Chris Fraser over the next couple years, I was able to trickle down to two. So, I've been on two meds since then, but I was very fortunate to—after my contact here at Cool-Aid with Chris Fraser, Dr. Fraser he was amazing doctor, still my doctor after all these years. Yeah, he's pretty much a lifesaver.

AH: Want to switch topics here for a moment. What was the governmental response in those early [inaudible] ?

CG: Wow, well, from going from Vander Zalm in the eighties who didn't want to talk about it or even acknowledge it, to the government where we had to acknowledge that we even existed and we needed help—we had to fight for it from the get-go. You know, so politically it was tough, but the organizations and the doctors, and other organizations, really gave us a lot of support, and they started funding our meds finally. By the time the meds, the medications come out, they were aware that they needed to get a hold on the pandemic, because it was spreading like wildfire. And our meds were being covered by government, so it was a blessing to finally get to that point where our medications were being funded—

AH: Were there hearings in the government or just representations to ministers and—

CG: There were, there were, yeah. The Health Ministers were definitely involved, and yeah, there was response, but there was also endless amounts of activism that was going on in the HIV community that never has stopped, since then. Right now, it's criminalization that we're fighting, that's still going on. And that we're fighting for – but no, it's been a never-ending activist kind of a…

AH: Can you describe some of that activism. What sort of…?

CG: I think just about not only politically but just educating people at large, you know, through your family, through your friends, through you know what people thought of HIV and AIDS. And it's just been an endless amount of dealing with stigma, with the effects of being long-term survivors, of isolation, of depression, of suicide, of—yeah, there's a lot of stuff going on. And how to make—where to go to access help, you know who would accept you even? In the early years, they were even rejecting dead bodies of people that are HIV in some of the mortuaries, so it's like it got to that extent where, yeah, you had to fight an angry kind of – open people up to what life with HIV and AIDS was all about.

AH: How much of that was sort of public action as opposed to one-on-one or family or things like that?

CG: That was tough. I think it's not everybody that was HIV that was open to wanting to talk about it or even wanting to let people know, you know… It was hard to for a lot of gay guys that were diagnosed with HIV who hadn't even come out to their family about being gay, let alone being HIV. So, when they started opening up about being gay and HIV to their families, we'd have guys walking into their support group who had been ostracized by their family because of being open about their diagnosis, let alone being gay. So, there was a lot of isolation, a lot of you know—and that's when the AIDS quilt started happening too and people were making quilts of people who had died of AIDS. I was fortunate to have seen the AIDS quilt—Canadian AIDS quilt—brought to Vancouver several times, where I've seen some of my mentors up there. But it was, yeah, it was hard to be open, and for me I was fortunate because I was surrounded by activists, and I was surrounded by… You know, you had to be – if you wanted change, you know, as that famous quote by ACT UP "silence equals death…" You know, it was very much like that for us in the early years. If we didn't say anything, we would never have gotten to where we did in those years, if we were silent and didn't say anything. We had to act up, we had no choice. But it's not everybody that chose to go that route. People were stigmatized, and you know, and even killed and brutalized by that, being so exposed.

AH: Can you speak about that?

CG: Well, there was a lot of brutality going on in those years, there was a lot of—the stigma ran deep, you know, the stigma being HIV positive on top of being queer, was a double-whammy for a lot of people, for myself too. It was like, if you were anti-gay or not prone to be very inclusive in your mindset, you have somebody queer come out as being AIDS on top of that, it was something that was, yeah, you had to be tough and you had to have support to go out there and stand up in front of government, in front of family, in front of friends, and stand strong, and let them know, share your story about what that was all about. That was hard. That was tough.

AH: Was there an increase in gay-bashing?

CG: Absolutely. Absolutely. You could walk around in the West End in those years before the AIDS meds you could walk down the street and see guys with Kaposi sarcoma, you know, it defaced you, it was evident. But then the queer-bashing was evident in not just in bashing itself—which happened—graffiti all over the West End about how this was god's revenge on the queers, and you know, it was like that was happening. And so, the only thing that helped was the coming together and organizing a support group for HIV positive people. That was the lifesaver for all of us in those years. But not everybody even decided to go that—people were very—were very—some people were still very suspicious and had a hard time coming out to even support groups. I met—when I was co-facilitating, because I was a nurse back in those years, I was doing my master's at UBC in Social Work – I didn't finish it because I was getting too sick—but the poz support group asked me to be a support in the support group, and I said of course. But there was some people that, they gave me that contact I made through them, through the organization, because they didn't want to be coming to a support group, they wanted to be more anonymous.

So, people responded in different ways that way, people wanted to be seen just one-on-one. They didn't want to come out to everybody or in the group. So that had to be honored and recognized as well. And not everybody dealt with it in the same way.

AH: But the medical community's response, you mentioned a couple things, Montaner and so on, but overall what was the response?

CG: It was slow-going. It was like, thank goodness we had a lot of good nurses in those years, you know. I just went to an HIV conference last year in Vancouver, one of the last ones that we've had for HIV positive people, and I was asked to speak with one of the other co-founders of the support group on Salt Spring Island of those early years. And during the talk I just asked the group, I said, "How many nurses are in the audience that were HIV positive in those years?" There was about a dozen hands that went up. There were some nurses that were HIV positive in those years, I was one. So, there was other nurses to that were HIV positive, that helped obviously. But Montaner, and the AIDS foundation at St. Paul's had started, so there was a lot of knowledge that was starting to get spread through the medical community. And we're fortunate in the gay community because the gay doctors were definitely much more in tune with how to deal with it and the medications that were finally being administered by the late-nineties.

AH: Did you ever run into doctors who refused to deal with it, or…?

CG: Yeah, there were some, and in those early years, there were some dentists even that would refuse HIV positive people, and yeah, there were some doctors. Yeah, they didn't know how to treat HIV in those years, those early years either. But I remember specifically being denied because of—dentistry—because of my HIV in those early years. Yeah.

AH: So, what was the public reaction to the epidemic? You mentioned sort of the graffiti in the West End, but was there intensification of discrimination and stigma?

CG: I think, yes, the ultra-right-wing, like I'm thinking of Vander Zalm in the late eighties in Vancouver who basically didn't want to give any credence to HIV at all, and to the right-wing it just seemed like it legitimized their feeling about not just gay people in general, but gay people being affected as well. It seemed to be a platform that they could use to increase their stigma against the gay community. But we were fortunate because there's always been in the queer community, in the community at large, there's always been people who had a bigger – who organized and supported us. The lesbian community was amazing in those years. The lesbian community just came out and supported the gay men especially. But there was also people in community at large that came out and supported us. So yeah, it varied a lot.

AH: So, how did your community, I guess define that as you will—the gay community, or the West End community, the choir—react to the epidemic?

CG: I think when I sang with the Vancouver Men's Chorus, I think we started being a voice for those infected, the guys infected with HIV, definitely. We'd started singing and doing fundraisers and raising awareness, and commenting and singing about stigma and so yeah that was, that felt very supportive. And a lot of the Gay Men's Chorus' all over the world have done that, supported the HIV community.

AH: So, was there a lot of fear in the gay community?

CG: Absolutely, there was a lot fear. Yeah, there was a lot of fear. I think it – to some extent, I think it created some kind of schism I think in the community where you know, the—all of a sudden there's—and it still exists to some extent today. I think there's those who are HIV and undetectable who are, for some gay people, they're still seen as uh… dirty, you know? And even though you're undetectable and you're HIV is undetectable, untransmittable, it's still a criminal offence. You can still be put in jail for non-disclosure. So, we're fighting that. But we're still fighting it in the gay community as well in our community about, yeah, the stigma. It's still going on, it's still happening.

AH: You mentioned that you were pretty far down with the AIDS, full-blown AIDS. Did you have any caregivers or loved ones who became involved in the HIV community, in helping?

CG: I was fortunate, I think, in my immediate family I tend to, I had a reaction with my family that kept me estranged from them for a number of years. There's one family member I stayed close to, but by and large it was – I was struggling to stay alive, and be healthy and—I had moved away from everything. Living on Salt Spring Island, I felt quite reclusive to some extent as well. And by that time, I had got very much into dogs, and I had dogs, and I was living a very carefree life, like walking the backroads of the country lanes, and I enjoyed that. It also gave me a lot of strength. But I also found a lot of strength in connection with other HIV positive people you know, and it's amazing how we came together to organize with each other. Like, I'd never guess that I would've co-founded an HIV support group, a non-profit with two women back in the mid-nineties with two women who were HIV. But it was my lifeline to keeping well. And we supported each other.

AH: It just wasn't in your high school yearbook.

CG: That's right. But it was quite supportive that way. And Victoria's got a beautiful history, with VPWAS and Persons with AIDS Society too, with membership and how they supported each other in the eighties as well. So, got a long history in this city as well for support.

AH: So, can you expand on that? What was instances of that?

CG: Of that support?

AH: Here in Victoria.

CG: Well, I think it was the way that VPWAS and the organization – well, VARCS too. VARCS and VPWAS and AIDS Vancouver Island and Cool-Aid, they all organized to help each other. You know, when I was Board Chair, I was amazed at how all the organizations came together to support the AIDS Walk, December 1st, or do fundraisings or fundraising to help our membership and get funds, or raise awareness through workshops. When I was Board Chair here, one of the ways I gave back was—I'm also a Massage Therapist—so the room we're sitting in right now was a room that I opened up when I was Board Chair here and this was actually a massage room. There's a massage table here. And when I was Board Chair here, we decided that we'd open this room for a wellness room and that's how we would—in all the years that I struggled, in the early years before the meds came on, was the only thing open to us was alternative medicine, alternative ways to help us. And to me, touch was one of those ways. So, in the nineties I got diagnosed, I became a massage therapist, and actually when I got Board Chair here, I asked if they would be interested in opening a wellness room to offer all different kinds of alternative therapies. And I've got my own massage table, so I started offering free massage at the office. And that was really a beautiful thing, to be able to start that here, and to offer that as well. And I'm happy to see that VPWAS is still offering that today, because that touched me. It was beautiful to be able to touch members in such a way where I could come into this room and you know, relax with them, and people that had never been touched before. Some people had never been touched, you know? Some people who weren't in relationships, or never gotten a massage in their life. It was both an honour, and it was a beautiful thing to have that happen.

AH: Did you ever do any school talks, or anything like that?

CG: A little bit. I actually became a queer drag nun a couple of years ago. I don't know if you've ever heard of the Sisters of Perpetual Indulgence? They've been around for a while. They actually were founded in the late seventies in San Francisco, and they started doing AIDS fundraisers in the early eighties back in San Francisco. So, the queer drag nuns, they're a non-profit, who are very much dressed in queer drag nun with painted faces. They very much take vows, which we did, and I helped found a group here, the Sisters of the Moist Broilie.

AH: Can you say it again?

CG: The Moist Broilie, like a moist umbrella. And I helped, I went to Love is Love in the high schools about a year and a half ago dressed as a queer drag nun with a few other nuns to expound on being queer. And that was a high school, in Victoria. So, we talked about what the nuns were all about and how we organized in the AIDS pandemic years. But we raised awareness of how to deal withbeing queer and stigma and depression and isolation and community, and family, and all those issues. So yeah, we talked to high school kids about it, dressed as queer drag nuns. So, it was beautiful, and then I opened the last AGM here just over a year ago, a year and a half ago, where I gave a blessing at the beginning of the AGM. So, it has its way of – throughout my life, being a queer drag nun or even Board Chair, yeah, I've had to talk. Before we gave an AIDS walk, I gave a talk to the public on HIV. It's a beautiful thing to be given that kind of position where you, you know, you stand in that and represent an organization of people that are dealing with HIV/AIDS and how that can really open you up to express how grateful you are to be sharing that information to the public, because I hadn't. I have an extreme amount of gratitude for having had those years, both on Salt Spring as co-founder there, and here as well in Victoria.

AH: How did the kids respond when you did that in a high school class?

CG: I think they were kind of mesmerized by that—but at the same time it's the youth, I'm—Love is Love was just started in high schools a few years ago. I mean there's been support groups for queer people in high schools for some years now. But being seen openly as queer, and you know being trans, and openly queer and trans at the same time, because we met quite a few trans. And some of our Sisters are trans as well, queer drag nuns. To be able to talk with them and share that with them, it was a beautiful thing and it was like the kids, the kids are teaching us, they're the ones that are quit the bullshit kind of—the kids—that generation, our young generation are showing us the way, how to be more expressive and more celebrate your queerness. Those days of hiding out and not coming out are gone – you know, express who you are. And don't be ashamed and be proud of that. So, it was a beautiful thing to experience, to see that, express that.

AH: Shifting gears a little bit here. How did the community deal with the burden of care back in the late eighties early nineties, when people were dying right and left, and the intense grief that must've been part of life then? How did the community deal with that?

CG: That was intense, but thank goodness for the poz communities like VPWAS here and the community. I mean there's – I think if you go in the welcome—in the main office here, you'll see a panel of names there. And I think been fortunate that we had community that came to our aid, that celebrated coming together to support. Not everybody goes there, not everybody that can walk in those rooms, in these rooms for that support, nobody has that kind of anonymity, or that wants that. And I think—but thank god for that—and thank god for those retreats at Loon Lake, and retreats and speakers that were given to us, and doctors and nurses, and lesbians, and youth and families. And you know, there were families too that came and supported their loved ones that were HIV positive and spoke out, so you know it wasn't all doom and gloom in that regard. There were families that came and supported, there were organizations that came and supported us. But it has never stopped the fight, the fight continues to this day.

AH: So, how has AIDS epidemic changed the community, the gay community and the general community?

CG: I think it—how has it changed the community at large, you mean?

AH: Well, start with the gay community.

CG: I think it's offered a place of – a safe place, first of all, for people who are HIV positive to come. It's offered a safe place. We can come and you can make an appointment to see somebody, you can come—whatever kind of scenario you feel that they could offer you on a personal level, a group level, an intimate level. They can refer you to resources, you know, that kind of thing, so they're there to—I think they've been a beacon of light, quite frankly, in the gay community. To—we have a lot to be proud of that we organized in those years to organize these communities, have been around for decades now. And it's a proud history of what we have. And those were fought with a lot of pain, and a lot of loss, but we can be proud of what we've done. And we wouldn't've lasted this long if it wasn't built on a lot of love and lot of support from the community at large as well, the gay community. And just the HIV community who has—there's some members here that have been here from the get-go, for over twenty-five years. Been a long time. Some same faces, in that office. Penny—how long has Penny been here?

AH: At least since ninety-six, that's when I first met her.

CG: Yeah so, and Peggy Frank, and myself, and other members in communities in this city too, members of this VPWAS as well, been here a long time.

AH: So, is the gay community stronger now than it was before?

CG: I'd like to think it is, although I think there's still uh—there's still—yeah, AIDS—queer community at large I think is. I don't know, in Victoria, we don't have a lot of organized gay community in this city. Vancouver has more, in that extent. But I think as far as – I think to have an HIV positive community in a place like Victoria says a lot about this city, and says a lot about the people that have been at the helm here—you know, Craig, and the others on the board here—I think it speaks a lot to the perseverance and the need for—and the need for this, VPWAS to exist. It still exists. And it's still happening in Vancouver. But I think the queer community still is strong, is still when I see Love is Love in the high schools now with kids and—but the gay community at large organized. I don't see that as much here, because I haven't been part of that, in particular. That's more evident I think even in the broader scope of what's going on in the world and I think the organizations—like I don't belong—I belong to a lot of organizations that aren't specifically gay, and I think a lot of gay people are like that. But we'll come out and be who we are and stand strong and that. Like I sing in a group, I drum with First Nations, they know I'm queer and there's a lot of queer people in that group as well. So, we're integrated, more integrated, I think.

AH: More accepted?

CG: Oh, definitely. Yeah.

AH: What about the overall community, not the gay community but the rest of the community.

CG: Community at large?

AH: Yeah, how have they evolved over these last—

CG: Well, I think you still see that—I think you can see the more right wing going more right wing and the left becoming more left politically at large right now, in the country. Especially around the world right now, in 2019, become much more polarized. And—but that's making us, you know, resist even stronger. I see the resistance moving much like the ACT UP movement in the early eighties when we were out in the streets fighting for help.

AH: But is there more acceptance of gay people, of HIV positive people?

CG: I think so. I think right now too, even in – you know, I do volunteering like I've been asked to speak at this group—I cook a meal in a group home for young adult males run by a group called Threshold here in the city—and I cook for them. And I was asked to come there by their house supervisor because it's my best friend, and I was asked to speak—and so I cook dinner and then we all sit down with these young guys and talk about anything we want to talk about. And one night I was asked to talk about my HIV. And I found that was hard a little bitbecause there's trans guys in that house as well. I found that very interesting that it's still isn't as receptive as you'd like to think it is out there. And it's still not as—yeah, but it doesn't mean that you have to shut up about it, or that you can't speak your truth, or speak your journey. You know, if anything, when I drum with First Nations every week, I', with the Unity Drummers, I'm astounded at how beautiful it is to allow sacred space where people can tell their stories without being interrupted, and but they're actually encouraged. And if they ask for help, we drum about it, we help them and we dance with them. It's like, that's how it is in certain groups, you're encouraged to share your truth, but it's not everybody that hears it in the same way, not everybody that wants to hear it or support it. I think stigma exists in our judicial system still. That's a huge fight in the HIV positive community that's being battled right now, so that's still going on. But the stigma exists even within the gay community and being poz as well, that's still going on, unfortunately.

AH: So, how's your perspective on HIV changed over time, personally? How's that?

CG: I think my perspective has changed for sure. I mean, I can't—you can't be a long-term survivor and not having it affect me personally. It's affected me deeply. I've lost two lovers, I've lost hundreds of friends that I've known over the years, and just the sheer amount of loss with all that accumulated loss. VPWAS did a beautiful—they offered a seminar on accumulated grief that was offered by Hospice Victoria a few years ago. Craig organized that. Beautiful to have somebody actually come in and acknowledge us, that long-term survivors have this accumulated grief in their life, just by the sheer notion of having survived a pandemic that took so many of us. And I think it's affected me in such a way that finds me—I suffer from some PTSD issues, because of that. Just the loss. The isolation, the grief, the depression that's gone on with it, has weighed heavy on me at times, and still does. I have lost some incredibly gifted and beautiful people that gave all of themselves, and died to that pandemic. You can't live through that and not feel moved to your core from that experience. You can't. I couldn't. And it still affects me to this day.

AH: As well it might. So, what about the new meds and all the interventions that are available now and that – let you relax a little…

CG: Well, the cure isn't here, and they're pushing for the cure. I think I've been lucky with my doctor, doctor Chris Fraser at Cool-Aid, he's helped me just bring my meds down to two meds. And I know there's other medications that I could maybe take that would maybe bring it down to one tablet a day, and—but I don't want to mess with my meds. You know when it's—if it ain't broke, you know, don't fix it. I'm fortunate, I've been able to go down to two meds and my quality of life is pretty good. I'm seventy years old, I'm doing pretty good with my life, I'm very involved in lots of stuff, lots of music mostly. But a lot of self-care, I think self-care for people who are long-term care survivors is a major issue and concern. And for me, it's got to do with touch and community and friends and engagement, and coming together with people that love and care for you. That's an important huge issue in my life. Those kinds of things, yeah. And remain connected. And remaining connected, where you feel supported and loved. I see my doctor regularly, and the nurses at Cool-Aid regularly, incredibly connected on the medical level as well. S, I feel incredibly blessed, connected on, in a lot of different ways—spiritually, mentally, physically. Yeah.

AH: Do you have any advice for health professionals?

CG: Ha ha, me? Advice? Oh, I don't know. To health professionals? I'm blessed 'cause when I see my doctor, he listens to me. My doctor hugs me. My doctor Chris Fraser, for me, is an amazing guy. And I've been blessed in my journey with HIV because I've had amazing doctors. Everybody from Montaner in Vancouver to Chris Fraser now and—no, I—to the medical community, I think, I know nurses now, I know doctors now, who are just incredibly gifted and giving. And I think for any doctor that can offer you their time—and I think I would give advice to guys who are HIV who don't have a good doctor—there are good doctors out there. And I've heard guys come up to me, "Who's your doctor? You know, my doctor doesn't know anything about HIV." Well, I say to them, "Get an HIV specialist." You need an HIV specialist that's a doctor, you really do, from my perspective. I mean you're—there are doctors who aren't HIV specialists who can get you on meds, but I think, to be cared for by someone who knows what they're doing and knows the HIV world makes a difference, for me. I don't know if I'd say anything, all I could say is, yeah, you're the caregivers, you're the ones reaching out to us, and I would say listen and have an open heart. Yeah, be a good listener. And I think people with HIV have a lot to say, have a lot to share, and not just on the medical level. I've been helped with – just recently I've had a really rough couple of years because I've buried three of my friends, and I found it difficult with that accumulated grief, and for the first time in my life I had to go on anti-depressants. I've never been on anti-depressants up until a year ago. And that was hard for me to take, and to swallow sometimes. Like, there's even stigma in acknowledging that sometimes. But I think that's another thing with—my doctor helped me get there. But he helped me really diagnose that, you know when I broke down in his office, and I said, "You know, if you can do that in front of your doctor and for your doctor to take care of you, you've got the right doctor," you know, who can really say, "Yeah, we need to help you here." So, doctors who can really listen and to really help you on that journey, because it—there's a lot going on with long-term survivors who are HIV positive.

AH: What kind of advice would you have for politicians, legislators?

CG: Oh my god. Politicians need our help, you know, and that's why we're doing – I think there's a lot to be said about poz people talking with the federal health minister trying to decriminalize HIV non-disclosure. We're doing that right now. So, I think it could happen. I think it's gonna happen, we're finally going to decriminalize it. So, it's like, I think the thing with HIV too seems like such a disease now that's been normalized. Okay, you've got meds, be quiet, stop, you know stop—we don't need to hear about you anymore. We still have AIDS walks every year, we still talk about it, we still need funds, there's still new infections, there's still, you know, marginalization, stigma, depression, suicide. There's still HIV positive youth on the streets, you know, homeless. Yeah, we're—there's a lot of stuff that was organized for a reason, those issues are there and they still exist. So, the politicians need to be aware of that, for sure.

AH: Any advice for future generations?

CG: I think the future generations are growing up in—with a history that offers them so much, especially in the queer and HIV positive community. I mean, I see the youth teaching us right now, I see the queer youth that are coming out in high schools, and even trans kids coming out in high school, trans kids coming out in junior high now, even younger. They're teaching us. They're opening our hearts, our eyes. It's pretty awesome to see that. When I went as a queer drag nun to Love is Love in the high schools and I saw how incredibly brave these students are to come out, but not only brave, they were proud, and being supported by their peers as well. So, I think they're teaching us. It's going to be an awesome generation coming up. Look at what's happening in the States with the gun lobby and what's—the kids who are organizing in schools. The first march ever by the students on the lawns. So, it's like, I think they're teaching us, I don't think I have much to say to them except it's like, you know, we're fighting for our planet on top of everything else right now, so it's like, those things are becoming more apparent with each day. And the younger generation, from what I see, has been open to stuff that we never thought would be possible. And I think they have challenges but they're meeting it—and I'm pretty amazed at what the youth is doing right now.

AH: Is there anything else you can think of that you want to say, that might be relevant to this?

CG: No, I think for me, expressing gratitude for the gifts that, you know, the HIV and queer communities have blessed me with over the years, and the incredible amount of support I've gotten from doctors, medical community, even the politicians—we have politicians in our city council that have come to our AIDS walks, that have supported us. I've seen people, and I've been blessed to see people that have support me, and I feel very honoured and blessed to have been touched by them, and supported by them, and loved by them. And that's always part of my Thanksgiving and my prayers, that I'm—I feel blessed that I've been connected to some amazing people both in being HIV positive but being Board Chair on numerous occasions. I've been blessed to meet straight and queer people that are HIV, and people that are doing this research, thank you. I want to thank them, because it's like, I didn't think—I didn't know this was going on, and do research on long-term survivors. I'm more happy to sprinkle some fairy dust on that one and to say thank you for doing this research, because I think it's much needed and it will be helpful for us as well.

AH: I think it – people today with PrEP and all that stuff forget how horrible it was back then, and I think the incidence of HIV has been going up, because people are too casual now.

CG: I think there's definitely a large part of that, there's a lot of parts where, you know—have sex, unsafe sex, and PrEP, yeah, there's a lot of that, throwing that to the wind. I know a lot about that as well, and it's like I—for me, the beautiful part of our history is all that loss, but there was a lot of beauty in that too. It's kind of a like a yin-yang to all of that. There's a deep respect, but a deep sense of loss but a deep sense of love there too. There was something that transcending the grief—it was more than just the grief, there was—part of that grief was incredible connection, incredible… yeah, honoured to have walked with some of these people that are now gone, and left us this legacy of incredible "don't give up," of ACT UP. And we're in the middle of an ACT UP kind of life right now. I mean, we have to act up our survival right now. I come from a legacy of that in the HIV community, so I'm indebted with my life for that. And thank you for this, for the opportunity for this. I'm very touched. And thank you.