“HIV in My Day” – Interview 63

February 19, 2019 [Follow-up Interview on February 27, 2019]
Interviewee: Adrien Ross (AR); Interviewer: Ben Klassen (BK)

Ben Klassen: Just sitting down with Adrien this afternoon. Thank you for being here. We’re really looking forward to hearing your story. I guess it’s still the morning, actually.

Adrien Ross: Just barely.

BK: Just to get started, can you tell me a little bit about how you started engaging in the gay community or in gay life?

AR: Well, I was a very green, naïve student at the University of Victoria in the early ‘70s, and it was in my last year – 1971, I think. I’m hopeless with precise dates but in my last year, I was aware that I was gay and was trying to figure out some way of actualizing that. So [laughs], I ended up in recommended public spaces that I read about in a gay newspaper from Vancouver, Rodey Green’s something or other, I think it was – I can’t remember exactly what it was called. But yeah, I started to meet some gay young people and interact socially and act out, and that was my initial connection with the gay community when I was still at university.

BK: Was it pretty informal back then at the time?

AR: Well, it was totally informal. There was a gay club in Victoria, but other than that, there was no focused – there was no community centre that I was aware of, no gay community centre. So, it was just meeting people, connecting sexually basically, hopefully making friends, which I did a bit of, and that was my first year of coming out. And at the end of that year, when I graduated, I ended up moving to Sydney, Australia and then New Zealand, so it was just a brief interlude at that point of being connected here in North America, in BC in a gay subculture. So, it was very superficial, sexual basically, with you know some developing friendships, which ended up being abbreviated by my departure and going down to Australia.

BK: Did you continue connecting with the gay communities in Australia and New Zealand?

AR: I was in Sydney working as a social worker for a year. I was in a relationship with an older man, [name], who was basically taking of me, and I knew that was a basically pretty dysfunctional relationship that had a best by date. So, after the year, I told [name] that I was not coming back from my holiday to New Zealand and left him and started my life in New Zealand, where I stayed for about seven or eight years and got very involved in the gay community. Yeah, I guess I got fairly involved in the gay community in New Zealand, in Wellington, New Zealand when I settled there and got into relationships and started living, started working. So, being involved in the gay community has always been a part of my life, but I’ve always been slightly ambivalent about it too, because I was always aware, from my perspective, of the issue of ghettoization, that some of the socializing was self-affirmative and self-actualizing and supportive, but part of it was withdrawing from the prejudice and the stresses of the wider community, so that was a very ambivalent thing. And I’ve always felt like I’ve wanted to be a little bit more courageous than that, so I was never really a gay activist, but I always out, and many of my friends were gay, but not all of my friends were gay. I felt like I was living – I tried quite consciously to live in the world as well as relate to people that I had things in common with that were sexual, and maybe that I didn't have in common sexually. That was really important to me, to not hide within boundaries. I don't know how successful I was, but I was conscious of not wanting to live just in the gay community. A real mixture there.

BK: And so, when you moved back from New Zealand, did you move to Vancouver then, or was it back to Victoria.

AR: I – it was a bit haphazard. I'm an only child and I had aging parents up the Fraser Valley, so I was always conscious that there was a kind of tug to come back to Canada that I felt I hadn't really reconciled and come to terms with. And so, in 1982 when I'd had a separation from my long-term partner in Wellington, [name], I came back to Canada for a year, came back to Vancouver, and started to work and connected with the gay community here at that time. But at that point, I knew that I was going to try and repair the relationship and go back to New Zealand and give it one more go for the Gipper, so to speak, and did that at the end of… So, I was here in '82 and '83, and I returned, and then I came back having given up on the relationship finally at the end of 1984, which coincided with my diagnosis with HIV when I came back – that's when I realized that I was infected. Hope that makes sense in terms of my movements at that time. So, I was ambivalent in terms of whether I was going to be staying in New Zealand, coming back here to live, so finally in late-'84, I realized that I was coming home. And coming home was a bit of shock when the diagnosis happened at the same time, so it was quite an emotional crisis for me at that time.

To move it forward, some of the losses I've had in my diverse gay community were losses that happened in New Zealand, friends who died that I was not able to fully participate in their passing, because they died with me being a continent and an ocean away. So, I was just realizing just thinking about this interview that I in some ways had a very messy coming to terms with some of my losses, some of my very close losses. So, that's… [long pause] As you can see, still with me. I'm happy to be aware of that. Something that I wanted to talk to you about was one of the phenomena for me of getting HIV and continuing to live life was the habit of thinking you've dealt with things, managed things, but very often it has meant putting it under the surface and carrying on with one's life, because I've felt like there's been limited opportunities to process things. And that's not blaming society or myself, but I've found that a lot of stuff still has not been processed – it's still there that's affecting, upsetting, has been sort of dealt with but still has a lot of feeling attached to it in terms of my experience, having been HIV and the losses I've had that have had an effect on me. Some of this has only been apparent to me because I've been asked to do something like this, much to my surprise that coping doesn't mean that you've dealt with things necessarily, so… I'm glad to have brought some of this stuff back up to the surface to maybe put it more to rest.

BK: I think that's been a common theme for a lot of folks is the rawness of this still, the fact that there is so much affect, so much emotion attached to this still for so many people.

AR: Well yeah, and it's – and I was thinking about exactly that – this should have been dealt with, there should have been support – there should have, should have, should have. And I don't think that's really in a sense true. When I came back in late '84 with the diagnosis, I very rapidly sought out counselling and participated actually helping in the buddy program with people who were very seriously ill with AIDS and wanted to come to terms with myself by helping others who were in worse shape than me. And so, on a conscious level, I felt I was really doing an awful lot to look after myself, but much to my surprise, there's been this real residue of stuff that has been there and no one has poked the stick to bring it to the surface, and I haven't poked the stick myself. So, in a sense, I'm just surprised that there's a level of stuff that has a real feeling tone that's still there, but I felt… I'm a retired social worker. I have been involved in therapy, in counselling, in all sorts of things – it's part of living a healthy life – and yet, still at the end of the day, a residue of stuff that's still there. It's been interesting for me to have it resurface and pay attention to it. So, I'm very glad of this opportunity to get this awareness, and that's all I'm expecting to get out of this is to get in touch with stuff that I haven't asked about over the years, that I've just moved on, and no one else has been really interested.

It's funny, I just – my partner and I just went out to see a movie the other night and had dinner with friends afterwards – it was *Bohemian Rhapsody: The Freddie Mercury Story*. And I had seen it already on an airplane and it was just a very detached experience where I didn't really get much out of it, but seeing it on the full screen, it also got me in touch with the experience, what had happened in those years, because those were my years of crisis and coping with the disease. And at dinner with very close friends, I said to them, you know, that it really affected me, that this was a big part of my life that I'd got in touch with. And they said, "Oh, yes." And then we moved on to other subjects. And it's not blaming them. I think it's very hard for anyone other than maybe the most intimate of partners to really attach to someone else's need or wish to unburden themselves, because there's a big load there, and I think that sometimes even close friends shy away from it because they don't know what to do with it, because it's not their experience. And so, I thought that was an example of why something doesn't necessarily get processed or is not encouraged to be processed by people that you feel close to. They just don't feel the cues or safety to approach that sort of thing. It's left to a therapist or one's own devices, I think, so it can be left very often. Just an awareness. And I don't feel like I haven't done my best to deal with that part of my life, but I think denial is an aspect of anyone's living, wanting to get on and think, oh, this is sorted out, and you just move on unless there are some triggers that make you realize that something is still there. I think that's something that this interview process has made me aware of is that if the cues aren't there to look after something you've gone through, that it can just remain there as a latent thing and not rear its head or whatever.

BK: We've been conceptualizing a lot of these experiences as traumatic experiences that people have a hard time talking about even, putting into words. And certainly, having those conversations with other people, they're not the types of conversations that most people have a lot of the time, because they are so difficult. So, we really appreciate you sharing some of this with us.

AR: Yeah. Even though I've rationalized it and understand why some things are never completely dealt with, but it's… I guess what I'm most curious about is after I was diagnosed, I was in some therapy groups that was focused on the HIV status that I had – have. And there were people in the group who were dying, and everyone else who was just terrified and didn't know if they were going to be dying or not, so there were these opportunities, you would think, to process. But very often, these were just hand-holding coping mechanisms and they did the best they could, but things were left, because once you've been touched and affected, it stays with you. That's how – and this is really off the top of my head, is that I have coped very well and not really felt like the way HIV has challenged me has in some ways held me back from leading a full life. Yeah, I'm surprised by the feeling level that is still there, and I'm glad I'm in touch with it, but I don't think it's held me back from doing what I want with my life. I may be fooling myself, but I guess I'm trying to say that there's probably nothing much more I could have done except maybe had more of an opportunity to be in touch with my feelings, but denial being a part of one's life, thinking that I had coped with it. And I think the extra problem for me is that many of the people I lost were lost in New Zealand or in Australia, although I did lose people here too, but that reinforced the there's nothing I can do thing for me, because I was detached already geographically from some of the losses.

I still had me and coping with my own feelings on my own condition, but I thought I had dealt with it [laughs], and have to a certain extent. I guess I'm not blaming myself for my humanness of wanting to cope and think, yes, I've looked after myself and things are fine, just being surprised that it's not totally fine. And that's okay too, to have these things come up is a very good thing, and to be aware of it. I'm glad. So, an interesting mixture. It's funny, I was talking with my partner before coming here today – well no, this was actually yesterday, we were taking a walk, and he was saying, "Well, you may end up wanting to process some of this stuff. You know, go back and see a therapist or something." I thought, "Don't be ridiculous. I'm going to use this process to tell my story, and that is really neat. I'm really looking forward to that." But even now, wanting to just put a package around my experience and move on is still something I want to do, because I don't think much more can be done to make it any better. It's good that I can feel what I've felt, but I don't expect anyone to make it better, what I've been through, what has been some tough experiences. I validate that and I don't want it to be away. So, in that way, I don't expect it to be sorted out, ironically, but to be aware of it has been good for me, to have had that opportunity to have this questioning that doesn't normally come up in my everyday life. That's therapy in itself.

BK: You mentioned that therapy group after you were diagnosed. Was that one of the first supports that you accessed at the time?

AR: Yeah, it was through AIDS Vancouver, I think. There was a co-led – two gay women facilitated the group for HIV positive – it was all men because at that time most of the people being diagnosed were gay men, and we met for probably about six months on a daily basis. Yeah, I did that.

BK: What other supports were you accessing early on?

AR: Um, I had been in – I was involved in counselling just for other issues. I wasn't necessarily focused on HIV. I had seen a psychologist and at one time – well, actually a couple of psychiatrists through St. Paul's to look at my issues of being an only child and coming to terms with leading an independent life, and you know, the issues I felt I hadn't completely resolved in terms of being my own person, I think. That was the sort of issue that I felt was not just being a gay man or my HIV status, I was coming to terms with figuring out what I wanted to do with my life. And so, I had been using counsellors and psychiatrists for that purpose for a couple of years and felt like it went as far as it could go. So, there was nothing else particularly in terms of the HIV status other than that initial group through AIDS Vancouver that I was involved in. The other thing that I felt was therapy, when I was helping other people who were dire straits with AIDS, I found that was a very powerful experience and I felt like helping other people gave me insights into my own situation. It was the same thing – I became a social worker when I came out of UVIC because I felt that this was a way that I could self-actualize myself as well as help other people, and it was the same principle when I volunteered to be a buddy for a couple of years with a number of people who were dying, as it turned out. So, that was also therapy. I felt like being involved in the community in some ways was therapy for me. I still feel that is very useful, helpful for me, not to be just self-absorbed and just talking to a counsellor about me, just me – me in interaction with the world has been helpful, I think. That platitude, helpful for anyone, I think.

BK: That would have been the early, early years of the buddy program, I imagine.

AR: Yeah, I think it was the beginning of the buddy program, yeah. And some of the people who were in the buddy program helping out ended up dying themselves because they were also infected people. I wasn't the only person who was infected who also wanted to help. So yeah, it was a strange time.

BK: It also must have been quite scary to see people who were quite sick. Was that frightening?

AR: Um… probably, but being a good rationalizer, I tried to figure out how to handle that kind of shock of having that experience. What I was struck with mostly was life's impermanence. I suspect this isn't the first time that you've heard this, that being scared to death can be a way of waking oneself up. As Samuel Johnson said, and I'm going to mangle his words, that the "thought of hanging tremendously focuses the mind." And so, seeing people dying and being terrified myself at all sorts of levels really helped me to make my life as purposeful as it could be. The dark side of that is, and maybe it's not just for me, I think that when I came back to Vancouver from New Zealand and had the diagnosis, I was, you know, I was aware of being very terrified of being alone, and meeting my intimacy issues with HIV was an awful situation for an awful lot of people. It completely alienated a lot of people in some ways. No one wanted to be your partner. I was both lucky and a little bit courageous in that I was always up front about being HIV when I came back and started dating, and that sort of thing. I was very lucky to meet my life partner at the beginning of '85, and I'd told him – I told Richard that I was HIV positive, and he said, "Oh, sure. Fine, you know." He really didn't know what it was all about. We fell in love, and as time progressed, he obviously understood more about what was happening with AIDS and HIV. Maybe he was in his own form of denial, but at the time, it didn't stop him from wanting to know me and connect with me.

So, that was a life preserver for me, but the dark side of that was that I was very terrified of being alone, and initially I was very dependent on the relationship because I was afraid of being alone. It took me a long time to be assertive and just be myself, because I thought the risk of being assertive and being myself was possibly being alone, because no one would want to be with me. That's not just an HIV issue, that's a personality, neuroses that I had as an only child, and needing security. I had worked on it with counsellors, but I think that HIV made me much more insecure in building relationships at the beginning. I'm in a very happy, satisfied relationship that we've both had to work on, but I think it was extra hard for me in the beginning, because I was just so terrified of being alone that I was grateful to be in a relationship to some extent, I think. And mercifully, it's worked out very, very well, but some of the needs that I thought I could try and fulfill in a relationship were needs that I needed to take care of for myself with my own issues that no one else could solve for me. But HIV made it much harder to reconcile and deal with because when you're scared, you – I, you know, tended to make just decisions to enhance my security, I think. So, that was something I did come to terms with, I became less afraid over time. I finally realized I wasn't going to be dying, I had to live my life, so that helped me to reprioritize not just being afraid, but just being assertive and doing what I wanted to do, and figuring out what that was. So, that's the dark side of being diagnosed, but I think I've also touched on, as Dr. Johnson said, it focused my mind. It really did get me looking at my priorities and looking after myself in more serious ways. I became a meditator, I'm actually a practicing Buddhist, and that happened slowly after I came back, and became involved in that spiritual community. And that was totally a result of being scared to death or scared into life, so that was one of the coping mechanisms, positive coping mechanisms for me, I think, if that makes any sense.

BK: Absolutely. I have a lot of different directions I want to go right now. So, you said you were very forward about your HIV status even in those very early days.

AR: Yeah, I guess I should put a caveat on that. It will come as no surprise to anyone that's gay or a civilized heterosexual that there are social situations or conditions in the world where it's safe to be out and there are places where it's not as safe to be out. I was always out about being a gay person in any sort of situation and felt comfortable with that, but my HIV status was something that I only shared with intimate, close friends or anyone in the gay community. And it's interesting, that was a great support that I could be that candid with people in the gay community about who I was in that regard. But in the heterosexual community, I felt I had to be very careful, because they wouldn't understand, and there was so much misunderstanding, misinformation, particularly in the early days, stacked on top of homophobia, that it was definitely not something that would make your life easier. They say that challenges make you stronger, but not all challenges make you stronger – they can wear you down, and that would have been one for me, I think. I just chose very carefully where I talked about that aspect of my person, so to speak.

BK: Do you remember what some of those mainstream responses looked like at the time in those early years?

AR: Oh, it's funny, I have one of the world's worst memories, but some things, you know, leap out just like they happened yesterday. And some of the experiences of – well, this isn't an experience of telling anyone that I was HIV, but I can remember going into a restaurant with some gay friends – my partner and another couple – and going up the stairs. And we were carrying some twisty balloons that we got at some celebration, and there was a young male heterosexual guy coming down the stairs, and he made the quip, "Oh, that looks like the HIV virus." Nasty smart aleck comment, which was just so absolutely cruel, but said so much about what he thought about gay people and someone who potentially had HIV. There was a whole nasty story just a little quip like that, which was just very powerful that stuck with me. Another experience – and these are all in a sense really superficial experiences, but with deep superficiality – I remember I was in my car driving through Stanley Park. I can remember where it was happening, and I was behind a pickup truck, and this was at the time when they had the Gay Games here in Vancouver – was that in '85, '86?

BK: I think it may have been a little bit later.

AR: It may have been a little bit later. And I can remember, again, there was a male driving this pickup truck ahead of me, and on the back of his pickup, he had a sign: "gay people should die" or "faggots die" or something – I can't remember exactly what the wording was, it was just something absolutely brutal. And it took all of my will power not to ram him. I tailed him for a while and honked my horn, and I really shouldn't have even done that, but I was just so horrified that someone could just without knowing another human being could be wishing vile hatred and no interest in some people's humanity, because of how they felt about that kind of person. So, I was aware that I was swimming in a stream where you would come across that sort of thing, and I guess the message I often took was be aware of where you want to expose yourself and be assertive, and where you want to just get on and cope and function. So, I looked for places where I could be myself. Like, at work, I was an out gay person. It's funny, I was working for the provincial government at a community mental health clinic that dealt with people who had been through the court system, involved with sometimes very heavy-duty, challenging problems, and they came to us for therapy, counselling, medication, because they had mental health problems. And so, I was working with a lot of very mature staff – doctors, psychiatrists, nurses, other social workers – but I never felt I was safe enough for me to talk about my HIV status, even in that sort of situation. I can remember a very charming nurse that I really was very fond of making a flip statement about being afraid of people who had HIV, and I thought, uh-huh, hm, I'm not going there. And not wanting to have to deal with the ramifications for being out without knowing where it would lead. I was just trying to [laughs]… get by.

And I know that I could have been part of an education process of broadening and widening people's perspectives, etc. Yes, but I felt like I had enough jobs in my life, so that was a conscious decision, I'm just going to stay quiet about my status, even in a relatively civilized, supportive environment. So, that said a lot about the nature of how I perceived society around me, that I couldn't be fully myself. And obviously that has tough consequences for anyone that encourages this not dealing with things that I guess maybe we started this conversation off with, that I was surprised that this opportunity has just got me in touch with things that had been beneath the surface for many reasons. And that, what I've just said, is one of the reasons why it has stayed beneath the surface, because a way of coping has been just to leave things unsaid because they can – sometimes the message was by bringing them to surface, you cause yourself more stress and problems because people aren't going to understand. I internalized this probably more broadly than I needed to, but that's something that happened is that I internalized a lot of stuff because of the general aura of ignorance that I perceived out there, so that had an effect on my coping mechanisms, too. Yeah, no, I'm sure that's right. And that's a bit of a new awareness for me, that was one of the effects of coping is just burying things for good, practical reasons. Nonetheless, consequences.

BK: Within the gay community, you felt fairly comfortable being out about your status and sharing that with at least your friends in the community?

AR: Yeah, yeah, and that was comfortable. I didn't spend a lot of time in the [coughs] – excuse me – in the gay community once I got into a relationship. I had lots of gay friends, but I wouldn't be spending time in bars or communal opportunities in the gay community, except for – you know, I was a volunteer at the gay community centre doing counselling for a year or a year and a half in the late '80s when I was back, just counselling, period, not about HIV or anything like that. But I had the tendency to – I have to say this carefully – the tendency to become a nest builder and to be in the relationship. I characterize a lot of stuff that was happening in the gay community was about gay people meeting other gay people to hook up – that was a major focus, I don't think I'm wrong in that, and I didn't want to be involved in that anymore. Obviously, I didn't need to, so I really didn't interact with the community in any kind of structured way other than, you know, with friends, once I was in the relationship with my partner. I was happy to do that. I guess part of me felt that part of the gay community was actually to be avoided because it was just focused on sexuality per se and having partners or having anonymous sex, and that sort of thing, and that was a hard enough habit to break as a coming out person where you had to be secret. Part of my coming out process was furtively having sex and that sort of thing, so that I associated that kind of conundrum or way of being in the world with the some of the activities of being in gay community. So, other than being with friends, and at the time I did some counselling at the gay community centre, I limited my involvement with gay life because I found potentially it was very narrow. [Phone rings] Sorry.

BK: I guess one of the things I'm a little bit curious about is that you were pulling back from the bars and bathhouses and stuff like that, but within your little community that you had within the gay community, was there stigma within that community around HIV? Was there fear around HIV?

AR: Yes, there was. There was, you know, internalized stigma and fear. Mercifully, some of the friends I had were HIV positive, but sometimes – some of my – it took a while – and this still happens that sometimes that's an intimacy that you don't hear about right away, it's after the relationship has been built that your friend will say, "I'm HIV positive." It still is something that doesn't naturally be part of the natural, "out there" discourse, I think. It still is, oh, is it something I can say, even with friends. But yeah, I mercifully had friends that fairly candidly from the beginning of the friendship told me that they were HIV positive. And I was very glad to have an HIV positive doctor, that was very self-affirming and reinforcing of my strengths and confidence in the world, and that really helped me get on with my life by being able to talk about some of my craziness. It wasn't therapy but having a doctor who was helping me with meds and willing to talk about HIV was a tremendous boon. I don't know – this is Dr. [name] – I'm not breaking any confidences. [Name]'s now semi-retired and he's been an out gay doctor, and he was on AIDS Vancouver, on the board for a long time. He was a tremendous positive influence in my health life, and ultimately in my mental health life, that I totally could be myself with him, and that was really great.

BK: When did you get connected with him?

AR: It wasn't right away. I'm not quite sure. When I first came back and I was diagnosed, I was with a doctor who's no longer practicing who had many problems himself – names will not be shared. So, it was probably a year after that – it was probably 198- late '86, '87 – probably '86 that I started going to Dr. [name]. Yeah, fairly early on, so a long-term support I had with him until he retired about a year and a half ago, so that was a really big deal. I was very fortunate. And many people in the gay community, that was a positive aspect of the gay community, that he didn't just treat you for your condition, he would talk about himself and his feelings and thoughts, and his situation. So, it was great.

BK: I do want to talk a little bit more about the medical side of things, but before we do that, do you think that being involved in AIDS Vancouver, was that a way of connecting with the community too for you?

AR: For me? Um, I'll be candid, and I don't know if I'm being fair – I found it very frustrating. I didn't see that there were many opportunities that I felt like I could do anything that was helpful for me other than – my volunteer work was satisfying, but there was a point where I felt I wanted to stop it, and I'm not exactly sure why I wanted to stop it, but after I'd been doing it for a year and a half or two years, I guess my life was just sort of filling up, and I had had enough with being involved with people who were dying. Maybe that was it, I don't really know. And there didn't seem to be anything else in AIDS Vancouver that I felt was an opportunity that would be helpful for me in terms of what AIDS Vancouver was doing in terms of outreach, etc., etc. So yeah, it felt like it was out there, but it didn't mean anything to me, really. Yeah, and I don't know what they could have done, or can do, things any more than what they have or had been doing, but yeah.

BK: So, that was kind of the end of your involvement with AIDS service organizations?

AR: Pretty much, pretty much. There was a self-help HIV group on the North Shore that I think I accessed through AIDS Vancouver. That was my last involvement in probably 1987. A group of HIV men who would get together just to talk about things, and it was peer-facilitated. It, like a lot of peer-facilitated things [laughs], and I've done that in other aspects of my life, it struggled to have focus and purpose, and I dropped out of that after a while. I ended up just finding out that there were no more things that I felt were a support for me, so I just got on with my professional life and the friends in my life and other things in my life, without having any gay community or AIDS focus directly. Once the medication made my life safe again and I was no longer afraid of dying – I will not minimize the relief and change point that was for me, to have that boogieman move backwards so that I could think like other people about maybe dying in a car crash or of old age, that was a big deal, I think, the arrival of good meds so that I wasn't terrified and other people weren't terrified. And so that I didn't feel like probably the counselling support that I'd initially grabbed hold of right away was something that I found useful anymore as well, I think. Yeah, I think that they probably – those decisions were in a cause and effect. When I felt safe, I felt I could move on with my life without having counselling, emotional support.

BK: And just before we move on from talking about that stuff, what did you actually do as a buddy? What did that role look like?

AR: It was basically just visiting. There was a – the people I was involved with, they were – there were three different situations, and it was basically just friendship – it was all guys were really just asking for. And with a couple of the situations, it was pretty close to the end and so it was pretty cataclysmic in that there really wasn't much that I could do, even in that kind of support. So yeah, there wasn't anything even practical, you know, in terms of bringing food or shopping or driving people around, it was just being a friend in dire circumstances. There were a couple of times when I was referred to help people with AIDS where you couldn't even get to base one because their life had become too chaotic even to have someone else new in their life to be a friend or to be a support. So, that happened as well, and that was really kind of frustrating and a bit messy. It felt like a very strange part of my life. I didn't feel like I was – except with one guy, [name], technically he wasn't part of the buddy program, but a group of friends just rallied to help [name] when he was on his last legs, and so for the last six months, we just kept in good contact with him and cared about him, but we didn't end up doing much more than visiting and being friends, and that's what it amounted to. And I think that's what generally seemed to be the need, even though it seemed like there was a huge gap in terms of how helpful one felt in those situations. Yeah, so the buddy program felt a little odd for me in terms of feeling like I was really helping, I think.

BK: But I guess some of those people didn't have a lot of other supports or were isolated.

AR: Yeah, I think so. And you know, I remember there was this couple that I became friends with. It felt like I wasn't just helping, there was a real level of friendship. And when one of the partners died, I kept in contact with the other partner for a while, and so it felt like there had been some kind of real connection because it was needed. So, that felt good, but I was always aware that it just really felt like, oh god, you're putting your finger in a wall that's falling down with a wall of water pouring over it – a very miniscule thing. That may have been why I stopped it. It just didn't feel like – it felt overwhelming for me I guess, maybe too hard for me to keep on attempting to help, with the emphasis on attempting without feeling like success.

BK: I realize that we're running out of time for right now, so we'll just find another time to chat.

AR: Okay, that will be fine.

February 27, 2019, Follow-up interview

BK: Returning for another conversation with Adrien. Thanks for coming back and agreeing to share a bit more of your story with me.

AR: Well, my pleasure, definitely.

BK: So, one thing that I don't think we talked about a whole lot a week ago was information and where you were maybe hearing about the epidemic in the early years.

AR: Yeah, I actually tried to focus a little about that after our conversation. I have to go right back to the bloody beginning. When I was still in New Zealand, 1984, I was – well, ’82, ’83, ’84, there were things that were filtering through in terms of what was happening, and I was basically just exposed to that through the news. But beyond that, before coming back to Canada in ’85, beginning of ’85 or end of ’84, I was in Auckland and I had actually been volunteering on an AIDS project that was set up by the Hospital of Greater Auckland where I was working for about eight months before deciding to pack it in and come back home. And at that time, there was stuff that was coming through from what was happening in San Francisco, and I can remember there was a video that the support group I was participating in was shown to us. It was called *The Shanti Project*, which was just absolutely remarkably powerful. It really amounted to giving voice to people who were in the epidemic in San Francisco at that time and encouraging them to share their experience. Fast forward to right now, ironically. That was really one of the most powerful things that could happen for me at that time, and this was before my exposure, which happened – oh god, about eight, nine months after that. But I was really aware of people and their humanity struggling with this issue, and how – you know, I was aware that there was really nothing that could be done except hold people’s hands at that time, and that was the tremendous power of that Shanti Project and how they were working with mostly men who were dying at that stage. I was just really touched by the humanity of just being present with the people who were talking in those videos, and that stayed with me.

And after that, when I came back to Canada, got the bad news, my exposure to information was primarily through the doctors that I was seeing. The other exception to that – god, I can’t remember the name of it. It was called “The HIV Update” or Bulletin or something that was out of Toronto that was basically a flyer that came out periodically, and I think it was available at the gay community centre. I don’t think it was online at that stage, because this was actually the early days of anything being online. So, this “HIV Update” – it probably had a slightly different name, but it was – I actually met the guy who put the update together. I met him in I think Toronto or San Francisco on a visit I was having to one of those places, and he was a friend of my partner, or an acquaintance of my partner. And this update flyer really had all the current things that were happening with HIV and HIV treatment. To the extent that it could be, it was very reassuring, or it helped keep one in the loop as to where things were going, what was useful in terms of what one could do now. It was quite an important document. Yeah, I tried to follow it for quite a while until – I guess until the cocktail meds regime came through and I didn’t need that kind of reassurance. I got my updates from good ol’ Dr. [name] at that point. And that was basically – other than periodically reading something in the newspaper, that was all information was that I was exposed to or felt I actually needed. Yeah, if I felt I was anxious or worried about something, I would go to my doc, because he was a specialist – [name] specialized in working with guys who had HIV, and he was on the board of AIDS Vancouver, so I felt like that was the best.

Slight addendum, when I was first getting hooked up with AIDS treatment, I was in touch with Dr. Montaner and his program to see what I was appropriate for and what I could do, but that didn’t really amount to anything other than eventually ending up in Dr. [name]’s lap so to speak. But again, Dr. Montaner was reassuring in terms of what was happening, and you know, how I was. He saw my blood work and looked at me in those early days, probably ’86, ’87. Yeah, I probably saw him a couple of times because he was doing minor trials and research projects at that time with people who volunteered. Yeah, it didn't amount to anything concrete in terms of – again, reassurance from the expert, one of the experts in the field. I think that was probably about it, all that I can recollect that stands out.

BK: And maybe some word of mouth within the community? Maybe that's more hearsay.

AR: Um, you would think. It doesn't stick in my memory as something that was tangible. Yeah, I had one or two friends who were, you know, who were HIV, who were taking meds, and so yeah, we would talk. I don't know if I was getting much information – probably was, because we'd talk about everything, and so probably the news that was out there probably would be shared on an informal basis. It doesn't stand out. I wouldn't go to friend and say what are you doing about this sort of thing? But probably that did happen a little bit.

BK: Yeah, I think the Shanti Project, just jumping back here, ended up being a model for the buddy program maybe.

AR: I would suspect because it sounded like that was what they were doing is that they were supporting, you know, people going through what they were going through as in the buddy program here. Yeah, I think so.

BK: And then information around transmission, was that starting to filter out as well – like safe sex and condom use?

AR: Well, it was, and again, I was mostly getting that through the paper and probably through this "Treatment Update" I think is what it was called, this news flyer that I'd been in touch with, and I guess that was – when it became evident that contamination was bloody hard to get, except through blood contact, that was very reassuring for me when that did filter through, that I didn't have to feel exactly like, you know, someone carrying the plague that people should walk around and say "unclean, unclean." So yeah, that was big news. Yeah, I did depend on getting that kind of information, definitely, from the sources I described – what was safe and practicing safe sex, that information came out fairly quickly. How it was absorbed into the community is probably another factor. I think that even after one was told that you were safe as long you weren't sharing blood products, there was just the whole psychological stigma thing still probably was an emotional factor in terms of how one felt about being HIV and talking about that with anyone, regardless of the scientific information, there was a whole level of prejudice and fear that one had to sort of try not to internalize, but you would a little bit, and just try to put it into perspective. These are the facts – people don't just go on facts, they go on fears and emotions as well, so I tried to keep a balance of that in terms of being reassured that I wasn't Typhoid Mary. So, the information was important to have, it was very important to have, yeah, to reassure.

BK: I imagine that some of the early uncertainties around – like it took them even a couple years to identify the virus, and then there was concern around certain types of practices – were they safe or unsafe. But as there's more concrete evidence around some of that, I imagine that would really change one's experience as an HIV positive person as well.

AR: It changed in terms of how safe I was to live my life and live my life with my partner, but it didn't – a lot of it just didn't filter through with the prejudice in the community, and I wasn't exposed to a lot of it because I wasn't going out with a megaphone and saying I'm HIV. But I remember being on a family holiday with Richard, my partner, in Florida, and there was an elderly relative who was of Richard's elder brother – the mother of Richard's brother's wife – she was staying in the house too. And one of the kids, one of Richard's brother's daughters gleefully, with a beaming face shared the information that [name], the grandmother, was not going to use the same toilet as myself because I was HIV. And I had put it out there that I was HIV, and this is the kind of consequence. You know, it was dealt with, and she was a neurotic, dotty old lady, and I had more pity for her than anything, but that was the sort of thing you knew was lurking beneath the surface with any kind of interaction in the wider community. You just didn't know what people thought or felt, so it was wise for me to edit in a lot of circumstances, you know, my condition because people didn't know how to handle it. So, it was my responsibility to handle it, and that's paradoxical, because I felt I wanted to be me, and you know, in family situations and intimate situations with close friends, okay, I'd expose myself as being HIV. But there was a level where I didn't want the stress of dealing with other people's prejudices and neuroses any more than I had to, whatever that means. Yeah, so I edited out to keep myself from having to explain and educate all the time, I think. So yeah, those prejudices did come out once in a while, for sure – probably still do.

BK: I suspect so, yeah.

AR: Yeah, I haven't had any charming encounters for a long time, so I don't know what that means. [Laughs] It would be interesting to know the general attitude in the public and how much more enlightened it is. It can only be more enlightened than it was in 1990s.

BK: We can run with the treatment thread because we haven't really talked about that either, so when did you start to encounter treatments?

AR: Not the faintest idea when it started, because I had a few years when I was counselled to stay off the drugs that were becoming available because they were toxic as hell and they did as much damage to the body as they did to the virus. So, it was the early '90s I think when my helper cell count was starting to dip that I was exposed to the charms of AZT or whatever it was, the equivalent. Yeah, I can't remember what it was called, but it was probably AZT for a while. I can't remember how long I was on it exactly. I should, because it was just hell on wheels. Even though I've not drunk battery acid, when I talk about it, I think this must be like drinking battery acid, and one was recommended to take it with peanut butter or all sorts of things to make it go down. But one had the idea or the feeling like you were taking a poison, and so it was actually emotionally really quite traumatic for me, and I can remember how awful it felt. And my partner, Richard, reminds me on occasion, "Do you remember when…" Being almost sick taking it, let alone it being part of the treatment. It was pretty, pretty rough. So, that was my first exposure to the first drugs.

But you know, again, I was so bloody lucky because I had friends or I was aware of people who were taking the early treatments and it wasn't helping, and they were going downhill and dying still. So, the med regimes, one didn't know what to make of them, so that I guess I probably felt, okay, this seems to be working for me, I'm lucky. How long is that going to last? So, I was aware that it was still pretty scary even to be managing the first treatments and seeing how things went. So, that was probably – I would think probably a year max before I got onto something that was less toxic, but I can't remember what the names of the new drugs were, but that was – that was a game a changer, because they were much easier to take, more comfortable, and they seemed to be doing the job. The downside of that is that there was a toxicity effect on the body, and I can remember talking with [doctor's name], Dr. [name] about that. I lost a lot of my facial body fat which was irreparably lost due to that, so I became much more gaunt and had to deal with a change in how I looked, which was for a while quite upsetting for me, and dealing with that, and once in a while, people's reaction to the change in how I looked. So, that was one of the factors with even the first cocktails and the toxicity effect. So, the beat goes on.

BK: When did you start to have a combination of drugs that you didn't have as many side effects with? Did you ever reach that point or when that was?

AR: Well, the change in the body fat issue, that happened quite quickly at the time that the cocktails were first around, and so this was probably the mid-'90s, and that happened quite quickly, and then there was no other side effects or anything else that I experienced, at least that I was aware of. One thing I've always wondered about in terms of the drug toxicity was the changing mental capacities and the way I thought and reacted and managed things intellectually. I think I had a sense that I wasn't as alert or as incisive in terms of mental exercises as I would have been probably before I got HIV and before I was on drugs. I may be fantasizing about it, but you know, I noticed that there was a change in my intellectual capacity and doing some testing on occasion in the 1990s when I was doing some stuff related to my job as a social worker and having some things I had to undertake. So, that was interesting – what's that all about? But at one level, they were really minor things of, you know, how much of my life is involved in doing testing and that sort of thing – thinking and feeling and just behaving in life didn't really change that much, except in testing situations I felt like I just wasn't as on the ball as I used to be. And no one has ever told me that it was because of these side effects, but I have this sense that it might have been. Anyways, something happened in the mid-'90s to make me less acute in some ways, I think.

BK: It's interesting that your doctor discouraged you from going on treatment earlier, because I think there were other doctors in Vancouver who were really pushing for early treatment, even in the late '80s with the AZT monotherapy.

AR: Yeah, well, I just had no symptoms whatsoever, and I think that I was aware of my exposure very quickly, and so that for all intents and purposes, I was functioning okay. So yeah, this was the advice that I was getting – you don't need it because when the drugs were available that they were so toxic, stay off them until you have to. Because I think – I don't want to speak for Dr. [name], I can't remember if he was saying this to me, that because this regimen is pretty tough on you, let your body do as much as it can, and when we have the indications from your helper cell count that your body's not functioning as well as it could, and the drugs will help, that's the time to get on board. Because there was no magic arrow that was going to kill the disease, so there was no point in, you know, battling it until it showed that I wasn't functioning well enough and I was on this downward slide. That's my rationale and I think that's what Dr.

[name] was sort of saying, and I totally understood that. Yeah, I didn't realize that from what you're saying that other doctors were taking other approaches, but you know, I was quite happy to [laughs] not be exposed to the battery acid earlier on than I had to be. It was horrific, just on a physical and emotional level, so I was glad that I didn't have to take it earlier than I had to – yeah, very glad.

BK: I think with the benefit of hindsight, the received wisdom looking back was that maybe it wasn't great to put people on treatment until they needed to be, as your doctor did, but of course at the time, this was all kind of unknown.

AR: Yeah, people were struggling in the dark, including the experts, and there were various opinions out there. But I really felt like I was getting a very wise, measured opinion from [name] and the other people at St. Paul's, for instance.

BK: What else were you doing to look after your health during this time? Did you ever get really sick?

AR: No, I've never had any symptoms whatsoever except for lack of mental acuity, which may just be the approach of senility [laughs] rather than HIV. No, I've been really, really lucky. I had nothing to deal with, nothing to deal with whatsoever – no physical things whatsoever. Oh, slight rejoinder, once in a while I would get some tingling sensations in my fingers. It goes away. And that's the reminder of the drugs in my system, but that's about it. That's about the only thing I've had an awareness of in terms of meds and effects of some. Pretty good as far as I'm concerned. I suspect that there have been other experiences with other people, but…

BK: Like, side effects from the drug regimens?

AR: Yeah.

BK: Yeah. Oh yeah, definitely. Even some of those early cocktails, they had some really, really awful, challenging effects on the body for a lot of folks. Yeah, the fat issue but also depositions of fat for some folks on some drugs.

AR: Yeah, people talked about how you'd end up with hump behind your neck, so I was waiting to see if I was going to turn into the Hunchback of Notre Dame, but all joking aside, I didn't have that effect. Yeah, pretty awful stuff.

BK: So, the fact that you didn't really get sick during this period, did that mean that for the most part through the '80s and mid '90s, was it like life was just going on? Was it kind of business as usual?

AR: Yeah, for sure, but I wouldn't underestimate the power of the reminder that you have to have bloodwork done every few months, and you had to see your doctor, and you had to monitor your condition, and your helper cell count going up, down, or whatever, was something that you always had to pay attention to. There were never any major worries but just that having to have that reminder from time-to-time was just sort of ultimately a reminder of my mortality and my good fortune so far, but that I didn't really know how it was going to work out. I was always being reassured that things were fine and that there's no worry that the drugs were going to stop working or that the toxicity would give some symptom which was just terrible to your body, but I was aware that they didn't know long-term what toxicity could do. Somebody could end up with a stroke or heart attack or something like that, so that was at the back of mind that there was perhaps the potential for that sort of thing, but I was never preoccupied by those sorts of issues. I lived my life, you know, very normally and healthily. So yeah, once I was on the cocktails, I felt like – I think this was in my first talk with you, Ben, that once I was no longer afraid of imminent death, I could just get on with things. And even if you are getting on things, there's probably a level of you just trying to repress the other things that could be happening that aren't happening, but maybe at a subconscious level, you might be worried about it a little bit, and just hoping that it wouldn't happen, and that sort of thing. So yes, I probably did a normal level of suppression in my getting on with things, too, and what effect that had on me, I'll never know, in terms of coping and suppressing the real anxieties. You know, I rationalized and got on with things quite well, I think – yeah, very well. But yeah, there might have been an undercurrent – there was an undercurrent every two or three months when I had the testing. I was always a little anxious about how it was going to turn out, that sort of thing, and it always turned out well.

BK: I imagine it must have felt like sword hanging above your head for many of those years, just wondering when it was going to drop.

AR: Yeah, in the early years, I think, before getting into the regime of the cocktail. Yeah, for sure. And you know, I was in support groups at that early stage and did some counselling in that early stage when – before the mid '90s, probably just to deal with that level of having that sword over my head. Yeah, and that was useful.

BK: I think we've already talked about where you were finding support. I know that after the first couple years you were no longer seeking out support from ASOs or anything like that, but thinking about mid '80s through to the mid '90s when you did still have some of these psychological anxieties, fears about how this was all going to turn out, who or what were your supports during that period?

AR: Well, other than the doctor I was seeing, there this group that was sponsored by AIDS Vancouver, which was co-led by a lesbian couple, Gayle Farmer and – I can't remember her partner's name – that I was in for about a year. This was probably – it might have been late '80s actually. I'm just hopeless with the exact chronology, but it would have been the early period before I got onto the cocktail. So, that support group, and also after that, experimenting with a peer-led support group that would meet periodically in North Vancouver near where I lived, were the only supports I tried out for a while. They were useful to do, but I was thinking in retrospect with the peer support group in North Vancouver that it was a real struggle for it to be supportive, because people didn't know what to talk about or how to enter into conversations. You could just see people thrashing around, including myself, and so that for me, I didn't attend it more than four or five times max, because it wasn't a place where sharing had some kind of sense of support and relief. There was more thrashing around, and that's really too bad, because there was definitely the need there, including for myself, but people didn't know how to – I suspect it needed a level of professional skill to bring people together to address things. It needed a little bit more than peer support to work well. Surprise, surprise, when you're scared to death or scared into life and, you know, you have so many worries and issues to cope with, and not just HIV, but just getting on with your life, and bringing that into a room with other people and their own perspectives, likewise dealing with things, it really does need a lot of skill to be able to help, because people at some level were immobilized by their anxieties, or we'd end up just saying, okay, I'm coping, that's fine. There's nothing more to talk about, and there's nothing more to bridge to things that are difficult or uncomfortable to ask for help with, I think. So, I think some of my prejudices is that some of the peer support stuff was not a wise solution for a lot of people. It needed more. So, I ended up using my own emotional devices, as well as ending up in developing a spiritual practice, which did some of that work for me as well, which wasn't AIDS related, but it was life related without pushing anything out. But that wasn't perhaps what would have been available or the choice of other people, so I'm not making a value judgment about what would have worked for others.

BK: But it sounds like your spiritual practice was part of how you looked after your health holistically.

AR: Well yeah, because one of the things about – beating the drum of Buddhism, one of the perspectives is to become more mindful, to be more aware of what's going on and not living in fear. Being able to approach your experience with loving attention and moving on through meditation and actually connecting with other people as well, having a supportive relationship with other people who are practicing with you. And avoiding barriers by going through the barriers, and that also meant I was always a very open person about my sexuality and my HIV status within that small spiritual community, so that was useful for me. And I don't know if with other people with HIV they found that within the gay community, that level of support, which you can characterize as spiritual or just people getting honest with each other. One of my definitions of spirituality is just being able to be honest and moving past fear, and I'm hoping that other people found they could do that in some way. It didn't have to be through a Buddhist practice, but I think that was very helpful for me, definitely, to have a holistic spiritual approach to my life and not have it segmented off – this is something to deal with and something over here, and it's on another table or something. Everything was on the same table as far as I was concerned in terms of my life and experience, interconnected, if that makes any sense.

BK: It's definitely something we've been interested in is where people found supports and how they cultivated resilience, and spirituality is something that has come up in quite a few of the interviews. Yeah, I hadn't thought of how that might relate to something like support within the gay community or peer support through some of these organizations, just that ability to be real with people and in community with people.

AR: Well, I think where it becomes an interesting issue is that anyone with HIV hits the wall. All of the coping mechanisms are just going to be thrown right to the limit, and I found that I didn't have the coping mechanisms to deal with this on my own. I had to find some way of receiving emotional, intellectual help as well as practical help. And I think that anyone with HIV had that issue where they found that they needed to find new things that were not in their bag of tricks that we have in our life. It was I'm sure an issue for everyone – everyone hit the wall, because it was the most stressful thing that anyone could have to deal with on this side of being alive, because you’re threatened with not being alive, and so that’s the scariest thing for any human being. So, that issue would have come up for everyone, how to cope with this and how to move forward, and I sure hope that everyone got that for themselves, however which way, through whatever resources. But I found that the best one for me was figuring out how I could be in the wider community and be myself and have a deepening awareness practice to look at everything, and not be saved, but to stay sane. Does that make any sense?

BK: Yeah, absolutely, that makes sense to me. And then outside of that spiritual community, were you drawing from the support of your partner, your friends? Was that an explicit part of your support system?

AR: Yeah, it was always myself, and I guess being in an intimate relationship with my partner has always been a tremendous support. And we laugh about it now, because when Richard met me, he didn’t understand what HIV was – I don’t know how he couldn’t. But we laugh about it now, but thank god he didn’t, because he wasn’t afraid of me, so that we went through this together as much as we could, and so that was always a really big part of my staying sane and functioning is having some place where I could be myself. But that took time to let down my barriers, to drop my guard and ask for his love and support. And he was always there to do that. So yeah, that was a really big deal, a very big deal for me, and continues to be.

BK: These are kind of obvious supports in some ways but important to articulate.

AR: Yeah, well, they are obvious supports if you use them. There are lots of people in relationships where they don’t feel they’re getting that perhaps, for whatever reason, or people are alone and they don’t have that intimate relationship, so they’ve got to find it elsewhere. We have to find it somewhere. Some of the stuff, we have to deal with ourselves, but part of that dealing with it is being open to the opportunity of other people can care for me, and you need to allow that to happen. And that’s a very important life lesson.

BK: I’m just going to take a look at my notes because I did write down a couple of things that I wanted to talk about. What was the government doing during this period? Do you remember what was happening at all on that institutional level outside of the medical field, maybe within the government in terms of how they were responding to HIV?

AR: Um… hm. I’m not sure in the early days. I got the feeling like the government was scrambling. I know, and we briefly touched on this, that in my work, I didn’t tell people I was HIV because there was a lot of free-floating prejudice even among wonderful, mature people. So, I kept that away because I wasn’t sure if that would impact my work status, I guess, in the very early days in the ‘80s and early ‘90s. So, I wasn’t sure what my status would be, because people in the work place could have early on felt threatened by me being there, or that sort of thing, so I think that was a conscious decision on my part, for the turtle to keep its head in the shell, so to speak. The other thing, and this is not exactly directly related to what you were saying, I remember in the early days, crossing borders – talking about governments. I was very anxious about being discreet with my medication, and my partner, Richard, was more anxious about it than me in some ways, but wisely so perhaps, because people were being turned away because they were HIV, even from the U.S. So, there was a lot of nuttiness out there in the late

‘80s, early ‘90s, until, I don’t know, the facts filtered through on an official level. But again, I was just – it was nothing I ever had to directly – I was never stopped at a border, I was never asked something that was uncomfortable, but I always knew this is something that could happen. Forewarned is forearmed, or whatever the right expression is. So, that’s the only thing I was aware of on a political government level in the early days. Yeah, nothing more than that really.

BK: Do you recall activism happening around HIV here in Vancouver? Do you recall seeing that at all?

AR: Um, yes. [Laughs] I didn’t – I never particularly participated in it. It’s funny, Richard and I had two very dear friends from San Francisco, and we went on holiday together and we were in Paris, and they went off to an AIDS demonstration, and we didn’t feel like we needed to. So, that may be my insularity – I was never political in that way, although I don’t deny that it was an important thing to do, but I didn’t participate in that demonstration or any AIDS demonstrations that I can remember. I feel self-conscious saying that.

BK: That’s definitely not my intention.

AR: No, I know that’s not. I think I felt like I would be looking for places where I could be real, and I did that to a certain extent, and that was the limits to my activism. Yeah, no, I can’t remember ever having participated in a demonstration per se, but I never thought anyone was an idiot for doing it.

BK: I think one thing we’ve noticed, and this isn’t scientific evidence or anything, but most people we’ve interviewed were not directly involved in that type of activism. They were doing other things.

AR: There was a lot of activism in the early days, because I certainly was aware of demonstrations and some very aggressive stuff to keep things in the public eye. I think to some extent, I felt like we were a bit more civilized in Canada and that when the government finally did figure out what was going on that we got supportive services here, like payment for drugs and no obvious discrimination, and it took much longer in the United States for that level of sanity and respect for everyone’s humanity to happen. I can still remember people like President Reagan being horrified about anyone who had HIV and saying dismissive things, so south of the border, I think there was a much more real battle to be met in the streets. And our friends from San Francisco were part of that, I think, because it was tougher for them down there. I felt lucky to be here in Canada, that was sort of a given, which can lapse into smugness, because we had our own stuff here, obviously, and no place is perfect, but I felt this was generally a supportive place in many regards. I always felt that.

BK: Even just at the most basic level, Canada having publicly funded healthcare makes a huge difference.

AR: Well, that’s just it. There were people in the U.S. who struggled to get their drugs. I can remember in the early days appeals for people in the U.S. asking us to send them drugs, just hideous stuff. So yeah, a much more humane, civilized situation we had here with public healthcare, for sure.

BK: I think we've covered a lot of the specific questions that I have. So, maybe getting around to large questions, maybe somewhat abstract questions, how do you think the epidemic changed the gay community? What the community looked like in the early '80s and what the community looked like later on – what role did the epidemic play in shaping the community in some ways?

AR: Not really totally sure, but I think that PWA and AIDS Vancouver became a real rallying cry for the gay community. For better or for worse it became in some ways how the community was partly defined, I think, which bespeaks the wider society's prejudice that to be gay means you're a potential HIV person, that sort of thing. But I think that the work that AIDS Vancouver and PWA did was transformative and very, very supportive for the community to the extent that it could make things better and help. I think they were, you know, tremendous efforts to help in the community and provide supportive places for people to go to. I can't remember the name, but there's the house near St. Paul's dealing with people needing palliative care and that sort of thing, that was initiated through AIDS Vancouver – the Dr. Peter Centre, and things like that. They were very important things that happened, and I'm not sure where that is now, because I'm not an active person in the gay community as defined, so I'm not sure what that is like, you know, now. But I think that in the '80s and '90s, it was a game changer, that within the gay community, people would stand up for people with AIDS or HIV and demand our humanity be seen. Yeah, they were pivotal, definitely pivotal. Where that is now, I wouldn't surmise.

BK: I wonder how much that maybe influenced public perceptions of the community in the sense that those organizations were such a clear example of the community caring for its own in this very powerful way. And so, if you'd maybe thought of this community as some type of superficial, hedonistic entity before that, perhaps that also maybe transformed some of those mainstream views of the community as well. That's pure speculation. [Laughs]

AR: Yeah, but beyond that, I think it was very good that those services were there for people in the community, regardless of the wider society. I think the wider society tends to pay attention to whatever it has to pay attention to and shrug off everything else, so I think the main effect of AIDS Vancouver and PWA and Dr. Peter's Centre was within the community itself doing really good things. More widely, I hope that it had some effect, but it had some effect on the ground, that's what counted.

BK: That was certainly the top priority. No, I think that's absolutely true that regardless of the impact that it had outside of the community, the most important impact was within that community and actually picking up some of the slack that mainstream institutions were not providing that type of care. There was this huge gap, and so the community was really stepping into that void and looking after the people who really needed care.

AR: Yeah, and it was a very necessary activism. And I'm slightly skeptical and cynical, when you look at society as a whole, there's so many factors going on, and so many different perspectives that it's very hard to affect things on a societal level and make progress, I think. It's important but it’s much harder to change, you know, the wider perspective of how we live together as human beings. I think it’s a toughie.

BK: One of the other things that we’re hoping to do with this project is to generate some intergenerational dialogue around HIV, so sharing with younger generations what this looked like in the ‘80s and early ‘90s. As someone who’s been living with HIV for as long as you have been, what advice or what lessons do you have to share with folks who maybe did not live through this?

AR: In the gay community?

BK: Sure, yeah.

AR: Hm… I guess I’m aware that it’s not an issue that’s gone away, that how we look after ourselves is always an issue whether we have HIV or know someone who has HIV, it’s a reality in our community and the wider community. It’s funny, I was struck – and this is a little tangential, but my partner and I have had the great pleasure of getting to know some younger generation gay men, and there’s a gay couple that we know who are twenty-plus-years younger than us. And both of them contacted HIV, and they’re managing and they’re doing well, and it came up that they shared, as I shared, as part of our friendship and intimacy, and as friends. And then I guess the only advice I’ve got is that we have to really not cut ourselves off and segment ourselves off and hide. I think that if we’re meeting our needs emotionally, spiritually, or whatever, I think we’re less likely to get into trouble, and if we’re using community resources, having friendships, being ourselves in an honest way, I think we’re going to get into less trouble. And when we are in trouble, having the ability to reach out and not go into shells is really just tremendously important.

I think that I got into trouble because I was – I’ll never know when I got infected, but I know that it was a very rough time emotionally in my life where I was seeking, you know, some kind of help by having sex, and not an unknown thing to happen. So, I think that encouraging everyone to be meeting their emotional needs in healthy ways and not having to hide, and I was in a time in my life where I didn’t know probably how to meet some of my needs in a supportive way, that I might’ve not gotten into the trouble and getting infected as I did if I had a more balanced life. Maybe I would have, because no one is going to be perfect, so I think that just ultimately it’s important for us to not cut ourselves off and to seek whatever needs or help that we have and satisfy them, and not feel like we have to close down. To be a human being means to have friends and to be part of a community, and that can take really hard work in terms of getting out of one’s comfort zone and getting out of one’s shell, I think for sure. But I think it’s really important not to be self-referential and selfish and to be involved with other people in all sorts of different ways. I think that’s a very important need. Be in all sorts of different relationships, I think. It can sound like a bromide but it’s very important to not cut oneself off and just go into an internal negative circuit or spiral, which can very easily happen with people when they’re in a crisis. That’s where being part of something beyond oneself is really important.

BK: I think I've covered the questions that I've outlined, but we always like to leave some space at the end of the interview just to ask if there's anything you want to add, or anything that you thought we'd touch on during the interview that we haven't had a chance to discuss yet.

AR: Well, I'm not going to surprise you, I might have alluded to this, Ben. The surprise for me is that it was – I've just been talking about connecting and being a part of something wider, that for a lot of gay people with HIV, they managed and coped, but to a great extent, because of the way society operates and the way that we function ourselves, that we just close off and just move on. And the gift of this kind of a project of asking people about their lives is something that doesn't normally happen for people with HIV. No one asks them about their HIV life and their experience, and it's not just about HIV, it's how they've lived their lives in all sorts of ways. And I'm shocked that I needed reminding that that was important, that sometimes people will not ask, and that's the way things operate. But you know, something like this project has been a very great kindness in opening up to some real needs that are there in the gay community for people who have had that struggle where no one asks. It's just sort of this sleeping secret of people just getting on, and that's not good enough, I think. So, it's been a real wake up call for me to pay attention to my experience and my memories and talk to friends about it. Since meeting you, I've been talking about what that experience has meant to me and tried to share a bit of that with friends who care about me, but I've had to initiate that, and it's my job to initiate that and keep that awareness alive.

So, what that leaves me with is just it's always an issue that people just want to get on with things and leave what's under the surface under the surface, and that leads to problems. So, from time-to-time, we all have to look at how am I feeling? What's going on for me? What has gone on for me? How can I look after myself? And not just be soldier in one's emotional life, just getting on with things, but looking for ways that you can keep in touch with your feelings and your thoughts and your memories. Getting back – the last thing I'll say is once a year, my Buddhist group and other Buddhist groups have a celebration of the Buddha's passing, and we get together at our centre and have a little ritual. And during that ritual, people who have lost someone in their life put pictures up on the shrine as a memory of what's gone on for them and what they've lost and what's still in their hearts. What I'm going to do tonight is bring to memory the people I've lost in my life through this tragedy and remember them as part of something that's still important to me, and carry on. [Laughs] But just to keep memories alive is something that this project has helped with, and I thank you.

BK: Thank you. Thank you so much for sharing all of this with me. I was really struck recently in another interview where someone, another long-term survivor, said no one has ever asked me what it felt like. I didn't know what to make of that. I don't know why we don't do a better job of talking about this as a community, as individuals within that community – that seems really problematic to me.

AR: Well, it is, but I don't have an easy answer to that. I totally agree that there's just something in the human mechanism to let denial take over. If one is functioning, that's often seen as good enough, and just to move on and not to ask any more. But this kind of a project is a symptom that other things operate in society at a societal level and at a personal level, like human-to-human like we're doing right now. And if we can just remember that it's there, that those needs are there

– it’s to always be asking questions and not make assumptions. And yeah, I was talking to a friend about exactly that, that he felt he had never been asked about his HIV status, and I sent him along to this project, and he’s participated. The need is out there, and you cannot wave a magic wand, but it certainly is thought-provoking as to how can we do better, how can I do better. So, that’s something I’m going to be left with without any easy answers, but the question is a big, important one, for sure.

BK: This is a one-time sit-down chat, and I certainly appreciate how valuable that is for some folks, but I wonder what a longer-term solution might look like. There are no easy ideas or solutions in that regard, but that seems like that’s a service or a gap that needs to be filled at some point for long-term survivors like yourself.

AR: Yeah, there’s no easy answer because it’s a societal issue in terms of how we function as people, that we tend to just get on with things and repress things – part of the DNA of human beings probably, and just being human. I think that the things that have happened in society since the ‘70s where people have started to experiment with looking after themselves in ways that are, you know, emotionally supportive, with encounter groups and spirituality and connecting in different ways is probably going in that direction of not just going to work and shopping and meeting your physical needs, but doing other things that meet other needs. But yeah, there is a huge gap out there, and making people aware of it is going to be half the battle, I think, that people need to connect with each other in more fundamental ways than they have been, because we don’t know what’s there, because we’re just so used to coping. Even people who are functioning well [laughs] probably could be functioning a lot better if they weren’t saying, oh, I just need to get on with things and not look at this or talk about that. I think that we do too much of that. We have to open up our hearts to our thoughts and feelings in ways that aren’t comfortable and figure out ways of doing that. And it’s going to be hard, it is hard. That’s a question I think that any thinking human being has, that it’s a problematic thing, but if we got the questions out there, if we could even put them out there, something will continue to be figured out. Yeah, this is a good sign, definitely a very good sign, and I don’t think it’s on its own. That people are curious about this sort of thing means that people think about these issues and how they’ve affected people, so may that continue and spread.

BK: Anything else?

AR: No, for now. And thank you again. This has been a really – a significant event in my life, as someone else said to you, to be asked and to be aware of these things. Wouldn’t have happened otherwise. And so, it was a great opportunity and left me something, you know, that I’ll continue to mull over and what I need to do in order to take care of my experience. A very good thing.

BK: Thank you so much. I really appreciate hearing that. I’m just going to stop this.