

**“HIV in My Day” – Interview 87**

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**Interviewee: Tim O’Neil (TO); Interviewer: Ben Klassen (BK)**

**Ben Klassen:** Great, just sitting down with Tim this afternoon. Thank you so much for being here and agreeing to share your story with me.

**Tim O’Neil:** For sure.

**BK:** Just to get started, could you tell me a little bit about how you first became involved in the gay community or started engaging in gay life?

**TO:** Okay, well, I grew up in Hamilton, Ontario, and I don’t know if you know, but a lot of gay people at that time – this is long before the Internet of course, so a lot of gay people, they met in bathrooms, you know, parks, that kind of thing. So, I guess that I could say that there was a bathroom in Hamilton where I grew up at the Holiday Inn where I met somebody, and he sort of took me to Toronto. Mind you, at the time, I was fifteen years old, right? There was a bar in Toronto – it wasn’t a gay bar – I mean, it was a gay bar, but it didn’t have alcohol. It was like an after-hours called the Manatee, and so I went there. He took me there one night, and you’d go there – the bar opened up at 10 o’clock at night and was open all night long till 6 o’clock in the morning, so it was just dancing, dancing, dancing. I met a lot of people my age, believe it or not, and that’s how I got involved in the gay community was sort of in Toronto. And then through that I met other people. So, that’s how I started there, and I moved to Toronto for a while. Then I moved to Vancouver not too long after that – about 1981, ’82, I moved here.

**BK:** So, when was it then that you were starting to engage in the community in Toronto roughly?

**TO:** Probably like ’79, ’80 – sort of around there. And that meant going to this bar, an after-hours club – I wouldn’t want to call it a bar. In the disco era, there was a lot of young people that wanted to dance, so there was a lot of clubs for younger people, especially younger gay people, that you couldn’t get into a bar. I think at that time it was nineteen, maybe even twenty-one – I can’t remember. You had to sneak in or borrow someone’s ID to get into a bar, but I went to this after-hours bar, and that was a great place. I remember I didn’t desire drugs or alcohol at the time because I was just so excited to be in a room where there was a lot of gay people, even though at the time I was very nervous there, very self-conscious, and I’d sort of sit there, but it was just great being in that crowd. You know, of course, this was pre-AIDS, remember, so sex wasn’t really an issue, you know? I mean, sexually transmitted infections, we didn’t really think about – they were all sort of treatable, so it wasn’t something to be concerned or worried about. There wasn’t the fear – I guess there wasn’t any fear. And nowadays I’m really thankful that I actually got to experience that, because most people don’t nowadays experience that. They’re in that fear of you know “Am I going to get something, or what’s going to happen?”

**BK:** Yeah, that must have been a very exciting time.

**TO:** It was, it was. There was – I think there was a lot more intimacy. You know, I mean, you do hear about nowadays a lot of times – condoms are great and everything, but it kind of – a lot of guys want that intimate and that skin-on-skin at that time. When you didn't have that fear, it was great. Although there was also that people were sexually hyper, I guess, you know. You could easily become – you could easily use sex as a way to feel validated, and I think that I did that for a long time. It became a way of feeling validated, feeling wanted, or just escapism – it was a drug. As great as it was, you know, there was still a lot of problems being gay at that time. I was fortunate enough that my family had a lot of acceptance. When I told my parents – I should also say that at about fifteen, I started running away from home because I didn't know – I didn't actually know why it was, but I would be running to gay centres, like I'd run to Toronto basically. Because I just – I guess that in a way I felt like I could be myself, which I couldn't be in Hamilton, even though I had this acceptance from my family. We went to this family counselling, and the counsellor was great. He said that, "You know, Tim is not going through a phase," because that's what everybody would say back then. It wasn't a phase and there was that acceptance, although when we got back from the counsellor, my mom had talked to my neighbours and they basically told them that I was gay. So, I lost a lot of friends. You know, this is the '70s mind you, so at that point, I started running away from home, because I felt accepted in home, but I felt rejected at school and other places.

So, I just had to get away from that at the time. And the gay community was great. Well, it was just fun. I just was having a great time. Like I said, there wasn't a lot of drugs, I didn't really drink – I smoked cigarettes, I think that was about it. Maybe some pot here and there, but I was just so hyped on being out and being gay and being sexually active. That became the past-time. And I think at that time – I don't know if it still goes on today – a lot of times gay people would meet – or I would meet... I should say my own experience is that you would meet, you would have sex, and then after the sex you would know if there was a connection. There was that intimacy that happened after the initial encounter, because that was a way of validating someone. I felt validated, so then I could be myself and then we'd have that intimate time together afterwards. So, it was a lot different back then.

**BK:** The community sounds quite different than it is now as well.

**TO:** Yeah. There was – it was, yeah, it was very different than what it is now. I don't know about support – I don't know if I was looking for – I don't know what I was looking for at the time, but I think I was thinking a lot with my penis. [Laughs] Like any teenager at the time, of course, when you didn't have the fear of anything, right? We never thought about anything really. I did have a boyfriend. I was seventeen, I had a boyfriend, and he was twenty-seven, and I didn't know that he was fooling around. He went on a trip to Florida one time and I think he stayed at steam baths. The following summer – we would go with my parents to – we had this cottage that we would go to. My parents actually let me invite him, so he came with us, with my family, and we slept together. Here I am, seventeen years old, mind you, and my parents allowed it, but it turned out he had – I believe it was syphilis. I'm not sure what it was. My dad ended up taking us to the – this was in Nappanee – he took us to get tested basically and treated for it, which is quite remarkable now that I think about it, because we're talking 1977, '78, and my father driving us to an STI clinic and getting treatment.

**BK:** Wow. [Laughs]

**TO:** But like I said, it was the therapist that helped my family to accept it, you know? So, I was very lucky that way, very fortunate.

**BK:** What led to you moving out to Vancouver?

**TO:** I just always dreamed about it, and then I had an opportunity to go to college here, so I applied, and I got in, so that's basically why. I had broken up with my lover at the time – he has since died of AIDS by the way. The late '80s he died of AIDS, many years later, so yeah. But that was – and a lot of those people that I knew back then have passed away, from Toronto – all those people. You lose contact with those people, but then you hear about somebody that passed away. I mean, Vancouver's gay scene and Toronto's gay scene, you know, we kind of knew each other. A lot of people were travelling back and forth, it was pretty common. I think a lot of gay people did a lot of travelling, and they would do a lot of, I guess you would call it sex travelling where you would go and stay at the bathhouse in one place, and the bars and the bathhouse, and that was part of the holiday, right? But of course, everybody would go to San Francisco, which was a huge place to go to in the '80s, being gay. So yeah.

**BK:** What did the community look like in Vancouver when you got here?

**TO:** I remember prostitution being really big. I remember you walked down Davie Street and there was a lot of people, trans people – there was lots of trans people. There was a lot of male prostitution. It was very lively, it was very lively. But like I said, I wasn't really a drinker, so there was – seems to be places to go... I remember going to a restaurant called Benjamin's – it used to be on Denman Street and you could go there and drink coffee all night, and it was a gay – I still know – the owners are still around. They haven't died but they're both... We used to go there and I used to meet people there, so it was a very friendly community – it was very friendly from what I remember of it at that period of time. When I first moved here, I hadn't heard about HIV for a while after being here.

**BK:** Yeah, because you said that was '81 or '82?

**TO:** '81, yeah, I don't remember hearing anything. At one point in '82, I took a trip to San Francisco, and that's where I first heard about it. That's where I first heard about a condition. I never really heard about it here. Yeah. So, next.

**BK:** Did the community feel quaint in comparison to Toronto, because Toronto was a much bigger city at the time, I suppose?

**TO:** It was, it was. And I wasn't heavily involved in the gay community in Toronto. I had gone to the bars, I had a lover, I wasn't heavily involved. And to be honest with you, I was just caught sort of hyper-sexual at the time, so I was going to – I don't really remember a bathhouse, but I remember meeting people at a bathroom, because like I said, that was really common before the Internet. That's how people met, or on the street. So yeah, but I really didn't like living there. I like Vancouver – I liked the way the city looked, the country and the mountains and everything

and the ocean, so that's why I came here. But when I came here, it was quaint. It was quite quaint, and it was – there was a lot of crossdressing, there seemed to be a lot of drag queens, and people were very loud. You walked down Davie Street, a drag queen would yell at you in a fun way, but it was kind of embarrassing – you'd be kind of... But it was... yeah, because they were the loudest. And of course, there was a lot of people who had a lot of problems with being gay, a lot of shame, so there was this big underground – you met some guy, and they wouldn't want... I remember going to one guy's place, and we had to make sure the curtains were closed before we kissed or did anything. So, there was a lot of guys who were in the closet, especially in the '80s – a lot of them were.

And of course, with HIV, there were a lot more that were in the closet, because you didn't – you know, fear. I wouldn't say it was a gay-friendly city – I didn't really notice that. The early '80s to the mid – even maybe till the late '80s, it was – I remember seeing those hats around that said “AIDS Kills Fags Dead.” Remember “RAID Kills Bugs Dead.” It was “AIDS Kills Fags Dead,” and you'd see that hat around. I remember you could see that quite a bit. I remember there was a lot of – a couple of times, I had an accident and I fell and I had to go to St. Paul's hospital, and each time I had to go to emergency or anything, one of the first questions I would get from the nurses there was “Are you a sex worker,” basically. They didn't say it like that, but they assumed because you're gay that you might be a sex worker, so that fear about HIV had kind of started. I remember getting that a lot and I thought, why are they asking me? Do I look like a sex worker? So, there was a lot of that at that time. I felt – there was also – not in the West End, it was very different. I worked over on Main Street and I remember feeling afraid for myself over there versus down here, and this would be middle of the day.

So, it was very confined, I guess that's what I would say. It was quaint but it was very confined. I think having transit in '86, that kind of opened things up – maybe that changed things a bit. But really, it was just a very confined – you know, you were very isolated in your community if you wanted to be open. A lot of – I remember for a lot of people, you couldn't be yourself in public unless you were in a bar. You risked getting your head kicked in – you had to be careful. And that of course, having to be only yourself in a bar, I think that opened up to a lot of people in my generation becoming alcoholics, because if you can only be yourself at home or in a bar, you're uncomfortable or you live in fear just walking around, so I think there was a lot of that. It was hard to meet gay people that were just comfortable with who they were, unless they were into drag or you know very flamboyant – unless they were really out there. It was just hard to meet normal – but like, today, when I walk around New West[minster], everybody's normal, so that tells me that a lot of people can just be themselves anywhere they are now. But back then, you couldn't – you couldn't be yourself.

**BK:** You said the first time you heard rumblings of this sickness or disease was when you were visiting San Francisco.

**TO:** I was visiting San Francisco and I was staying at a motor – well, there was a flat or place above the motorcycle shop, and it was actually a gay motorcycle shop, and it was in the leather district of San Francisco – they called it the Folsom. So, I was there, so these guys were talking, and I remember going down, and we were all just sort of talking. And they said they heard about this thing and they heard one person died of it. So, that's basically all I knew about it, and I don't

remember seeing anything else when I was down there. Do you want to know when I first heard about it here in Vancouver?

**BK:** Sure, and also how this was making you feel at the time, I guess?

**TO:** Um, I really didn't equate it to being a gay, sexual thing – I just didn't see it as that. For some reason, it didn't – I wasn't – there was no fear, anything like that. There wasn't a lot of knowledge around it, right? We didn't even know if it was sexual. So, I just didn't – I sort of thought – I guess when I first heard about it, I sort of thought it was like a cancer that anybody could just get. Like, somebody could somehow get cancer, 'cause what it was kind of looked at – it was looked at as sort of cancer. So, it was just your luck – did you get this disease or was it hereditary? I didn't know. So, I kind of saw it as that at the time. And how did I feel? It didn't really faze me heavily at that time. It just wasn't big enough. I wasn't into the news or watching the news, or anything like that, so it didn't... And for a very, very, very long time, people with AIDS or HIV hid – you didn't know. I mean, of course, you could tell physically, but they sort of hid themselves from society, so you know, all these... I remember one time – yes, I do remember one time there going to see a pride parade and there was a bus with PWA – persons with AIDS society, and they were all riding on the bus. I remember we looked at them and thought, hm, okay, some of them look kind of ill, but it just – it wasn't a trigger of fear, not till I came here, not till I was living here.

After I visited San Francisco, I came back here and then I really started noticing it in about – well, the first person I knew was '83, '84. He had had shingles – he had shingles. He was somebody – at the time, we were doing MDA at the time, I remember. He and his partner were selling the MDA, so we'd go to their house and we'd get it, and then we'd all go to the bar at the time, and this was 1983, '84, somewhere in there. And he had shingles. He was a very, very active person at the bars, at the tubs – very active, really wonderful guy, wonderful guy. I remember one year, I did the Jerry Lewis telethon – here, they were collecting money and it was on the phones – and he was the only person that saw me and pointed that out, and I was just so touched. But he had shingles really bad, and this went on for about two years – he was very, very in pain, but he had AIDS at the time. We didn't know – he didn't – you didn't really – people didn't mention that they had AIDS at that time that they had it, at least here they didn't. So, I went to his funeral and he passed away, and that was really the first person that I knew of who had it, but then within weeks of that happening, people were dying. I remember seeing – am I supposed to go onto this now?

**BK:** Yeah, of course. It's meant to be pretty open.

**TO:** So, there was a paper around here called *The West Ender* – I don't know if you're familiar with that, *The West Ender* – and every week it would publish people that passed away. And I remember, we'd go to the bar, we'd see people, and then the next week, or the week after that, we'd see them in the newspaper. And what I learned later is this had to do with PCP pneumonia, so I don't think they were using – it wasn't until the late '80s that they started using those sulphur drugs. So, at that time, that meant that HIV was basically a death sentence. It wasn't something that you could live – you didn't talk about living with HIV until that treatment for treating PCP came, where everybody was taking it. Up until that, it wasn't like you lived with

HIV, you know? But then after that, you started living with the condition, even though you were dying at the same time, but you had that survival. This was – you’d see this person at the bar – I knew this one guy at the bar who worked the door, and you’d see him healthy as – and then the next week, he was in that newspaper. He had just gone. Which – and some of us thought, you know, maybe that would be a good thing, because it wasn’t a survivable disease. You didn’t want to get sick. It would be better just to be, you know, dancing one month and then dead the next. It seemed like a more compassionate way of dying, although I didn’t know what was – I didn’t know what it was going to be like to live with HIV. For them to live with HIV back then, I didn’t know how hard it was going to be. I didn’t know that at the time.

So, that was – so I think when people started living with HIV, then it became really hard. Up until then – remember, I was negative at the time. I didn’t know until the ‘90s. So, until then, they were just gone – it was sad, but they were gone. But then, when people started treating PCP and started living with the condition, then that became a whole – really a series of problems and issues we were dealing with, with our friends. My friends, like a lot of them developed that AIDS-related dementia, right? The trouble with living with HIV at that time was that it was really kind of back and forth. That person was well for a while and then would get really ill – well and then get really ill. And then I noticed a lot of people had changed – like, they were alive, but they weren’t the same person. Mentally, they had changed. A good friend of mine had a Madonna party in which he started putting all these pictures of Madonna on top of one another on the wall, so he had that AIDS-related dementia. And it was very hard because it would be like, you’re with – I don’t know if you’ve been with people with severe dementia where you’re with them and it’s not the same person, but it felt like that. Or there was a lot of anger, anxiety. Yeah. It was a hard thing to live with all the time.

Things got really bad in the early ‘90s – I think that was probably the worst for Vancouver. I think San Francisco had – their problems really started in the ‘80s, but it hit us – I think the death rates went up quite a bit in the early ‘90s. That was memorial after memorial. And I think the hardest thing I had was not being able to grieve at that time. You had to remain strong, you know, for your friends. And also, my job was also starting to do – I had done my nursing at BCIT and I was doing care for persons with AIDS at the time. And I would do homecare, because a lot of Filipino women wouldn’t go to people’s – a lot of people just wouldn’t go. So, I was working tons doing that. And that – I think that a lot of times, I shoved my feelings down, or I’d drink – I’d have a couple of drinks. There was this work and then escape – that was basically how I coped living in what I would call like a Holocaust. Living at that time, it was just work and escapism – drink, some drugs – whatever I could – sex – to get away from that. And I felt at the time, even though I was HIV negative, I figured I would be – I just knew I would be, and I don’t think I really cared if I was. I really don’t think I cared because it wasn’t – it wasn’t a pleasant place to be. I’m a person with a lot of empathy, so when I see somebody in pain, it’s very difficult for me to not feel maybe what that person was feeling. And so, I don’t really think I cared that much about myself, and if I got infected, well, you know... Of course, when I got infected, I didn’t think like that at all, but at the time, you kind of just thought, well, why would I want to live in this kind of a place?

And there was no real hope at that time, and especially in the early ‘90s – there was really no hope. It wasn’t until ’95, ’96 that things changed. I just always felt like there was this cloud

above my head – like a dark cloud, like a rainy Vancouver day, and it felt like that all the time. I remember standing on Davie Street and seeing people in walkers and wheelchairs, and at the time, I totally forgot that they were my age. I thought that these were just elderly people, because the West End always had a high elderly population, but I didn't realize, you know. It was a very grim time. I also remember seeing some people – actually, going to the '80s, some people that I knew, and they knew me, but if I saw them on the street, they would sort of hide, because they had – they were ashamed and of course they were living with the disease and the stigma at that time. I remember seeing faces, and they'd see me and I'd see them, and they would hide or they wouldn't talk – there was an awful lot of that. I also had a lot of trouble just being happy – just smiling, because if I smiled or laughed, there was a sense of guilt. How could I be happy with this all going on, knowing that I'm going to go to a memorial here and one there. So, I'm just going all over the place. That's alright?

**BK:** Yeah, that's totally fine.

**TO:** [Laughs] I think the hardest time was I spent many, many days seeing friends and going to St. Paul's hospital. And there's a long hallway when you walk in the Thurlow [entrance], and that hallway always sticks out to me, even today, because I could see people I knew coming in, and there would be a panicked look on their face, and you knew that they were going to see somebody that was – you know, the nurse had called and said, "This person is going to pass away. You need to get here." And you could see that panicked look, and I'll never forget seeing that – there's a certain panicked look when you know that a friend's going to die, when you know that somebody's going to... So, I saw a lot of that, that panic. So, when I walk in that hallway, I can always – I'm waiting for that person to come along whose lover is there. That was really hard. So, I was also taking care of – I had a roommate, or a couple roommates for many years – we lived together for ten years. And one of them – both of them were diagnosed in the '80s. One of them is still here today – yeah, he's fine. But the other one, he's the one that died in '93 or '94. Like, his illness went on for years, and I was the primary – his sister and my other friend, we were the primary caregivers for him. And we had been through dementia. He had – we were all living together, but then he decided he was – he did have PCP, he got out of the hospital, and we had the oxygen tank at home, so we were taking care of him at home. But then he started getting the dementia and he wanted to move – we were living over on Commercial Drive – he wanted to move to the West End at the time and get his own place. So, fine, that was all done.

But in between when he moved and when he died, he was going in and out of Normandy Hospital. I don't know if you know – that was an AIDS hospice over on Arbutus. It was – there was a nursing home there – there is a nursing home there called Normandy. Well, they had a separate ward for people who had HIV, or AIDS at the time. So, he was like the only one that got in there, but actually, a year after he was there, he got his own place again. So, he was – so, that's what I'm saying. The illness was so up and down with people. You didn't know how – even though they say, you know, you're diagnosed, you could live six years, ten, whatever, you really didn't know. Somebody could get sick right away and they'd be gone or, you know... You were constantly treating these conditions. So, I took care of this guy for a long time, and I was taking him daily to St. Paul's hospital for ganciclovir, which was the treatment for – what is it called? AIDS retinopathy, the thing that caused people to go blind, right? And then this treatment, which was two bags a day – so, when you think about people living with HIV back

then, it consumed their life. They were totally defined by their illness, because you had to go to the hospital, or you'd go blind. So, their whole life was consumed, and the caregivers were all-consumed with, you know, taking care of that person. It just wasn't a disease that you got better, but it was – you got better and you were fine, and then, bang, you were down again. I think that was the hardest thing.

Sometimes – I remember saying this to several people, and talking with the families, “We wish that that person would pass away,” because you couldn't stand to be on this not knowing what was going to happen. And not knowing what was going to happen mentally. Some people were very angry. When I did homecare, there was some very angry, angry people, and maybe they had a right to be. Thirty-two years old and facing death or facing all these health complications – pacemakers, I mean all kinds of things were going on. Being robbed of their job, their career. You know, this is the time they make money and get up in their career, and it's, bang, now you're dealing with this. At Normandy hospital, there was a lot of people that were alone because of course there was a lot of people being abandoned by their family and friends. I mean, I have to admit that one time in the '80s, we had this guy over and he was HIV positive – just friends. And I do remember throwing his coffee cup out. I didn't have the knowledge. This was before I went into nursing, so I really didn't have the knowledge back then, so that fear was very big here. [Long pause]

I remember the first time I went into Persons With AIDS or PWA at the time. It was their first office and it was down on Hornby Street, way down near the beach. And I remember going in there and seeing maybe 100 people – I couldn't believe how busy this organization was – I couldn't believe it. And some people that looked like they had AIDS, and some people who looked relatively healthy. I actually went there because one person I was taking care of, I was trying to find help for him. I think at the time, I was looking for hope – like, maybe there would be something that... And I remember there was a lot of hope, believe it or not, but it was a lot of this Japanese cucumber they were talking about – this was an early... Some type of cucumber. It was more holistic. There was a book that came out called *The Cure for HIV and AIDS* by some woman – I don't know – and I remember getting that book. It turned out to be a fraud. She's now done the cure for all cancers, which turned out to be a fraud. But there was a sense of hope in some cases, more than in the '80s. I think when Septra or the sulphur drugs came out, there was that hope that started, because you weren't dying – you weren't alive one week and then dead the next, so that changed a lot. What else do I remember about that period?

Well, like I said, I emotionally was all about escaping. I did develop a lot of depression. I think I was living with it but didn't know it. Because I didn't really grieve – there was just – like I said, there was no time to grieve. You were on to the next person. You didn't think about yourself because you were always caring for somebody else, you know? I think I developed sort of a co-dependency – maybe helping somebody else really helped me. So, there was a depression, so I think I got started on anti-depressants as a way out of it, but that was just sort of a band-aid. It didn't really deal with the issues of grieving – that was the big thing. I was too young to – I don't think I even knew what grieving was at the time. I hadn't lost anybody in my family, so I didn't have that. I felt very empty. I just felt very empty at the time. I didn't think I had a right to be happy – I didn't think I had that right. It was just – seeing other people sick, seeing other people care for somebody who was sick, walking around the West End and seeing people in wheelchairs



all the time... You'd be having a good day, and then you'd see somebody in a wheelchair, and you knew that that person was gay, very thin, very gaunt – you weren't happy. You know, you couldn't – it was like that was taken away. That was taken away.

And of course, the government was – there was huge issues with the government I remember at that time. I remember when my friend who was sick, we would have to take him to emergency all the time, especially when he lived alone in the West End. We'd be taking him to emergency because something would happen, and they would ask us so many questions, and we thought, why is this...? You know, "What's wrong with him?" "Oh, he has AIDS." Well, why did they not know that? It's like he went in there and it was like he was somebody who came from out of province, and this was the person that was just there last month, or this was the person that was just here the other day getting ganciclovir and you don't know who this person is? You don't have a clue and you want to know all the meds, and of course, he was on I don't know how many meds at the time. You know, we had a docket full, and it was all kinds of things he was taking, because all they could do at the time was treat the symptoms – they weren't treating the disease at all. So, it was very frustrating. It was frustrating, and I'm sure for him it was extremely lonely. I could actually see in a while, I could see why he wanted to move away from us because he just wanted to be sick on his own. I'd go to his place and help get him washed or wash him, and he would only get up to have a wash and then go back to bed, and basically stay in bed. And then he would get better, and then it would be like, let's live, get better, and he'd be better for a month or so, and then it would be back to sleeping eighteen hours a day. So, it would be this... He lost a lot of friends because he looked sick – I remember that.

You know, I have to say that as I said, being gay in the gay community, your looks are your value. You know, it means more than money, how you look at that time. I don't know – maybe it's changed, I don't know, but at that time, you were valued by what you look like, and if you looked good, you had friends, you had people to talk to. If you didn't look good, you know... There were many nights when I'd go to a bar and you could see a guy crying – you could see somebody crying because you knew that that person was alone, you knew that person, nobody's going to want you. Of course, gay men have always been noted for being rejection sensitive. There's the rejection of being rejected, but there's also this – I know for myself – rejecting somebody else, so there might be a lot of pity sex. You know, even though I don't like you, I'm still going to go because I know how much that rejection hurts. So, I can understand how that person might have felt standing in the bar that was having a good day – that was another thing, you had good days and you had bad days, you know, health-wise. It's very odd for a thirty-three-year-old person to say, "Oh, today was a good day." "Today was not such a good day." So, I often felt for a person that was rejected. I think so much that I did have a boyfriend that was HIV positive – it didn't bother me at all at the time. It just didn't really bother me. I don't know why, but it just didn't bother me. And he's still alive today, so that was a long time ago. At the time, I just felt the rejection. I think I felt a lot of things, but I kept it down. I didn't want people to – I just didn't want to deal with it, I didn't know how to deal with it. Nobody taught me how to deal with death.

**BK:** When you're in the midst of a crisis of this magnitude, there's not a lot of time for introspection or dealing with one's own interior state.

**TO:** No. And that's had a huge impact on people, people my age. Like I said, most of my friends and that, all we did was go out and drink, or do drugs. When we had the time, that's all we really – we just thought about escaping from this. I didn't want to be around this. I mean, I guess I could say it was like a prison, especially when you knew a lot of people. It was like a prison. You were seeing death all around you, the illness all around you. How does a young person – how do you deal with that? How do you even know? And there wasn't support – there wasn't support for... I don't remember any support for the caregiver. There was support actually for the people living with the condition, but for the caregiver or the nurse or the – man, you just shoved it down, shoved it down with a drink. You didn't really – there wasn't that kind of support, you know? There was – I remember going to a support group for elderly – you know, people that were taking care of their parents. I remember going to a group like that one time, but I don't remember ever going to a group that was helping to support that – yeah, there wasn't that.

**BK:** It's not like it was just your job. You were doing this professionally, caregiving for people who were HIV positive, but this was your life outside of your job too – your friends, your community.

**TO:** It was easier going to work for – I mean, it sounds selfish, but I was getting paid. You know, there was some compensation there, not that I wanted money for doing it for my friends. But I wasn't having an opportunity to be in my twenties, I wasn't having that opportunity to be in my early thirties – there wasn't that opportunity to just have fun and be carefree. There wasn't – you couldn't – you were scared, you know? Not – I wasn't really scared about getting HIV because I assumed that I would like everybody else. I mean, now when I look back at it now, I think of it as I was just being myself in that generation. I really don't blame myself for that, it was just what I grew... It just happened to be – it could be like the black plague – it just happened to be in my generation, that was it. But there wasn't happiness, there wasn't really happiness. There was some good times. I think when my two roommates came back positive, that kind of changed everything, and that was 1986, '87, somewhere around there – that kind of put a dark cloud. So, I saw a lot of people that became positive back then and into the '90s that they went in two directions – they went one direction where they got into the drugs and alcohol, they really increased the amount, so they were looking for that escapism. I saw other people do something totally different. One of my friends that's still around today, he opened up his own business. He was collecting old furniture, he opened up a store. He actually did this while he was – before the treatment and everything, he was doing this. So, some people – it seemed like some people said, okay, I'm going to do what I need to do. And then some people, I'm going to go have fun, I'm going to go party until I die. And then some people, of course, they started their own business – I've seen two of those.

So, at least when I became positive, I knew that I could go two directions, so it gave me that idea, although after I became positive, I didn't think about anything besides HIV for two years. It took me a long time to come to terms with it. They didn't have the same support that I had in the '90s when I found out that I was... There was – PWA had really – there were counsellors there, there was peer counsellors. You could go there to talk to somebody. At that time, there was nothing – it didn't seem like in the '80s there was a lot – there wasn't a lot. It was the doctors saying, "You're positive. You need to get your affairs in order." And nobody wanted to hear that. I think that I was reluctant to get tested for a long time because I had seen people that tested

positive, and it really hurt them mentally, that – it was almost not worth it to find out, you know? Why? It's not worth it. A good friend of mine tested positive, and then I thought, okay, I better get tested.

**BK:** When was that?

**TO:** That was in the '90s. That was the early – '94.

**BK:** So, that was the first time you'd actually been tested?

**TO:** No, I tested in – I was down in California for a while and I had a lover, a boyfriend, and he tested and then I tested, and I tested negative. I think I sort of started frequently testing but then I kind of stopped for a while, and then I tested again, and that's when it came back positive.

**BK:** It makes complete sense to me that people would not have been super keen to get tested in the mid '80s when there was nothing you could do to combat the illness.

**TO:** Well, being tested and coming back positive was a death sentence. Even though you showed no signs, you were asymptomatic, you showed no signs or anything, the mental – what you were dealing with, you know... But I do admire some people that found out and still went on, started living their lives the way they wanted to live it – not how they think they should be but how they actually wanted to be. I think it was a motivating factor. But I've seen more people get very depressed and suicidal and get heavily, heavily into the alcohol – that was the whole model to escape. And like I said, my friend, when he found out, he just started drinking more. They'd go out and they'd, you know, get sloshed pretty frequently. So, that just told me he was escaping, you know? And of course, MDA and meth, but I don't think it was called meth at the time, was around – that became big. Maybe toward the '90s, that's when it became...

**BK:** Obviously, in the earliest period, you were talking about when you first heard about this illness in San Francisco, there's not really much knowledge about what this actually is. When did you begin to encounter some information around how HIV was transmitted and how to prevent transmission? Was that information starting to get out there at that point?

**TO:** Well, in 19- - I'm going to say '84, '85, we were all at the bar, at one bar – I can't remember what bar it was – and they were saying that they need to talk... A group of doctors had arranged a bus that took people from the bar, and they took people to this forum which was out on the east side. And it was a bunch of doctors from San Francisco. It had been epidemic down there, it had already really hit hard, and they were warning us. So, they were coming to us and they were at this forum. We didn't – we thought – for some reason, we thought we were going to a party – I can't remember what. We were going on this bus from the bar, and it was a school in East Vancouver, the auditorium, and all these doctors, and they were warning us about HIV. But they didn't say it was a sexually transmitted – I don't think they did at the time, so this was very early on. They didn't say at the time that it was sexually transmitted – I don't think they knew. I don't even think at the time – they weren't even calling it AIDS. GRID or something – was it GRID? Gay immune deficiency – something like that. That was the first forum that I remember going to, and that was quite – I mean, they were taking people on a bus to get that

information out. Not long after that, there was a show on CBC called *The Journal* with Barbara Frum back in the '80s – she's now died – in which they did a whole series on AIDS. That's something – it's on YouTube. They did a whole series on the early – on the AIDS epidemic. It was out of Toronto, and there was doctors from Vancouver, you know, and a lot of the talk too was hemophiliacs – they started talking about hemophiliacs. And it was about going to school and there was a lot of talk about that on there. So yes, I remember watching the whole series for like a week on CBC, *The Journal*. So, that was – those were the first times I really started hearing about it.

But as I said, in the late '80s, early '90s, especially in the '90s, early '90s – just before '96, that was when it was really every day it was gloomy around here. And I remember standing on Davie Street just wishing and wishing that there would be something – wishing for what is actually happening today. I mean, it's remarkable to see this in my lifetime, you know? To see now they can even prevent it. I mean, that was just remarkable, it was remarkable to see that in my lifetime. But at the time, I remember standing there just wishing. I remember one day, after seeing people in walkers and wheelchairs – and then you'd go to the eastside and you'd see "AIDS Kills Fags Dead" on those hats. So, you – when I look back on it now, how did I even get through that? Living with the discrimination or the stigma, people dying, not being able to grieve – you know, I developed a lot of depression. You know, if I got into a relationship, it was sort of trying to find someone to rescue me from all of this – I'll meet you and maybe I can go away, maybe he can get me out of this.

I did go to California for a while, just really to escape being around this. I didn't want to see it. And I don't think I really wanted to live, really, because I didn't really care about HIV. I really didn't want to live at the time, because why? Why would you want to live a life that was like living in a Holocaust camp? Why? What's there to look forward to? There was nothing to look forward to. Nothing. I just remember day after day after day, just another cloudy day. It was really like that. Yeah. And it became so normal – it became normalized. You kind of thought, well, everybody's like that, so you didn't really – I think the only salvation were drugs, alcohol, and antidepressants, really. And now, I look back and I say, thank god for that, because if I didn't have that maybe I wouldn't – maybe I would have not cared. I think also studying nursing, that probably saved my life, because I might have gotten HIV long before I did and may be not here today.

**BK:** So, I guess that's probably where a lot of your information around transmission and stuff came from, from nursing school?

**TO:** Well, when I was going to nursing, remember, AIDS was very new back then. They were more about universal precautions, that was the thing was universal precautions. When I went into somebody's home – like, I would go to somebody's home who was dying of AIDS at the time. A lot of times, it would be they were waiting to get into palliative care, or they would go to Normandy Hospital, and they were full at the time. So, you'd go to somebody's apartment and it would smell – you'd smell urine and piss and shit, everything. Of course, you'd smell all that. You were dealing with the person that was dying, but I remember often dealing with the family or the lover, so you were trying to give emotional support to that person as well as just being supportive of a person that was a lot of times, more than not, they were angry, angry, angry,

angry. And I don't know if you've dealt with an angry patient, but it can be very difficult. You can end up feeling pretty bad – you end up feeling pretty bad yourself. I remember a lot of that. I had a guy that I went over to his place and he had just come to – he was born in Vancouver but he had lived in Japan as a teacher, and once he found out he was HIV, they wanted him out of the country, but just before that, they burnt his mattress, they burnt everything in his apartment, because especially over there, there was that kind of fear. And he loved it over there, he loved his job. He was so angry that life had dealt him this now. He was just – I'll never forget the anger, and he directed it a lot at me as the person there. And I mean, I think I knew well enough that I didn't blame him for it, but I do remember feeling guilty about this, I wished he would pass away. He's so sick, so angry, and I'm sure there was a lot of people who felt the same way, you know a lot of families that felt the same way.

It's bad enough dealing with someone who's so sick, but to be so angry and abusive – somewhat abusive, you know – what do you do with that? How do you...? You can't blame them, but this person is being verbally abusive with you and you're trying to be caring. That was very difficult. I mean, being honest, I knew other people that were sick and had become very, very angry, and I remember in the back of my mind, this one, I hope he goes next, not... I remember thinking like that a lot. Very confused. You didn't wish anybody dead, but you weren't wishing them dead, you were wishing them out of the pain that they were in, and that was – I felt very guilty about that for a very long time, you know? Actually, bringing back the amount of guilt I felt just being not sick, being healthy, that survivor's guilt, that plays on you a lot. That really hurts a lot, you know? I think I've kind of resolved that now, but at the time, like I said, just smiling and laughing, and catching yourself and saying, "What am I doing? How dare I?" How dare you be happy? How dare you smile or go out and have a good time? And you didn't tell anybody you had a good time if you went out, because you didn't want – you know? That has stayed with me for a number of years, even after, some of the residual of that, the survivor's guilt. Of course, a lot of people who have been HIV positive for a long time have that today. So yeah. What else do I remember about that?

**BK:** It's not like you were withdrawing from the community either. I'm just thinking about your feelings around that guilt. Like, you were really diving in and helping out in a lot of different capacities, so to be investing all of yourself into helping people and to still walk away feeling like it didn't help, or you feel guilty still, it must have been just awful.

**TO:** It felt like I wanted to – you know, I felt like the kid that wanted to run away a lot of times. And I did for a while. I met a guy, he lived in the States, and asked me to come to California. We travelled a little bit, and it was all about getting away from this – it was just I gotta get away. And you know what? We drove to Yellowstone and it was like I could breathe again – it really felt like I could just breathe and relax and not have to think about this and not have to worry about it. Because it was your work, it was your life, it was your friends, it was your family. So, I think that was quite common. People would just – you'd see people exit the community a lot. You knew it was there. It's funny years later that I go to a positive group and I'll hear people that lived in that the same period that I did and didn't even know that AIDS existed – really didn't know. Lived right here in Vancouver and really didn't know it existed. And I think what happened a lot of times in the '90s especially – in the '80s it was very prevalent, but in the '90s, people with HIV hid. If you were diagnosed, you didn't want people to know. You didn't look

too good, you stayed at home – you didn't go out, you didn't socialize. So, it's almost like the great epidemic's going on, but I don't see it, so I can understand how these people felt that I didn't even notice that it was around, because we have to hide ourselves. You know, with HIV, you've really got to hide, you can't...

I do remember my friend, when I said that he was looking for an apartment, he wanted to move out, he had a hard time finding an apartment because they weren't renting to gay people. There was this open discrimination that we're not going to rent to a gay person because they're going to die. That happened a lot here in the West End, so it was very difficult for housing for people. And of course, jobs, you couldn't be open about your HIV status, let alone sometimes you couldn't be open about being gay in the '80s. Yeah, I remember in the '80s too, I had this friend, this girlfriend, and she'd go out with these gays, and she'd say, "Don't let them know you're gay," because this guy was obviously homophobic. It was accepted, you know – there was nothing wrong with it. Of course, you don't talk about being gay – you could be gay, but you don't talk about it. And then, of course, HIV, you didn't want people to know that. Even other gay people, you didn't want them to know that. I think, you know, there's a lot of internalized shame with just being gay – there's a lot of shame that people internalize. But what I've noticed through the years for a lot of people living with HIV is they might have had that shame prior to their HIV diagnosis, but once they became positive, the shame that they felt about being gay became shame about being HIV, because I see a lot of people that became positive who wouldn't even go to a gay pride parade, but once they became positive, they were out in the community and out in the pride parade, but all that shame had been transferred to HIV now. I think that happens a lot, you know? So, that internalized shame is just transferred to another condition. I think that's really common.

There wasn't a lot of ways to resolve that shame, especially when I was growing up – there wasn't a lot of groups or anything you could go to. It was really the AIDS epidemic that created all of this social support, so that was the good thing is that there was a lot of social support starting in the '80s, which really helped with the stigma. There was of course PWA and AIDS Vancouver. At the nursing home, at Normandy Hospital it was... There was a lot of shows, a lot of drag queens – there was a lot of money being raised. You know, at all the bars, they would have drag shows. All that money wasn't going to the drag queen, it was going to the AIDS organizations, you know? That's a lot of good stuff that came out, and it was drag queens that kind of started getting that all started. They were the ones that were out there on the frontlines trying to help, and lesbians who were trying to help when a lot of us were just too scared. We just lived in – you did live in a sense of fear of getting it. I mean, I became like, oh, I'm going to get it anyhow, but I still had that fear. I still had nightmares about it for a long time, nightmares that you come up positive – so I had that. But yeah.

**BK:** You mentioned that there was this fear and stigma within the gay community too to some extent.

**TO:** There was. There was this term – "Don't go out with that person. He's dirty." "Dirty" was the term often used. Of course, we didn't know who was positive, who was negative – we had no idea. You just assumed everybody was. Yeah, I think that stigma came out of the fear that I'm going to get sick or... I think also that things – people became a little bit more compassionate

after that Ryan White – there was a sense of compassion, so that was... I mean, he did an awful lot for people, for AIDS around the world, that little boy. You know who I'm talking about? He got turned away from school, and Elton John was...

**BK:** He was a hemophiliac.

**TO:** Yeah, he was hemophiliac. They didn't want him to go to – in the States. I think that had a huge impact, especially for people with hemophilia. But in the gay community, the trouble was that of course, like I said, your physical appearance, that meant more than anything. And HIV changed your physical appearance dramatically. So, I think that that's – I think I've probably been angry at the gay community for that whole relying on physical appearance and not who the person was. So, when I went out with a guy who was HIV positive, it just didn't occur to me. I mean, there was a lot of very naïve people. I think in some ways it was a very uncompassionate time, but there was a certain level of compassion. I've seen the HIV stigma grow, especially in the '90s, even with treatment – with treatment especially after '96. So, I think it's grown a lot since then as people have lived with the condition, right? I think it's also one of those conditions, if you don't have it, you don't really think about it. Do you know what I mean? If it's not part of your life, why would you think about it? If it doesn't affect you – I mean, I don't really think about multiple sclerosis. I think HIV is the same thing.

And the knowledge, it's changed so much, and the treatment has advanced so much that it left a lot of people behind, so there's still that stigma that, oh, that person's dying and I shouldn't get involved with anybody who has HIV because – they're just not up on it, which I don't blame them. Why would you even know these things? But maybe if you're active in the gay community, you should know – you should have a good idea. I think a lot of people were like me, they just didn't want to be around it. You know, they didn't want to be around people that had it. In a sense, because you know it was in the media – they just didn't want it, just didn't want it around their life. I think also in the early '90s when the movie *Philadelphia* came out, that had a huge impact on people, you know, people that I worked with. I also at the time, after that, I was also working as an adult – in the early '90s I was working in adult daycare with seniors, and I couldn't be open about being gay – I couldn't even be open about that, except with the staff I could be, because it was a medical field. But a lot of them, there was a lot of homophobia and there was a lot of fear or misunderstanding around HIV and AIDS at that time. And I was actually working there when I tested positive, and so I immediately told them at work, and they didn't have a problem with it. I mean, of course, there was a good understanding by '95 that – there was a pretty good understanding. I mean, some of them asked me to use a different cup, I remember that.

**BK:** Even that's a little odd in '95, isn't it?

**TO:** Actually, it's not, no. We didn't have – the Internet wasn't very big, so people weren't getting all kinds of news, it was just what you saw on TV. There was a lot of homophobia still coming out of the US, so it was understandable. Like I said, if you didn't know about it, if it didn't affect your life – these were heterosexual people and elderly people, I'm sure they never even gave a wink about HIV, about anything about it. Anything else in the '80s... [long pause]

**BK:** Dating an HIV positive partner at the time, was that type of relationship, serodiscordant relationships common at the time?

**TO:** Yeah, you know what, it wasn't uncommon. I remember going to a lot of people's – there were a lot of couples that were – one was positive and – actually, one was dying of AIDS at the time and the other was just fine. That happened a lot. It very rare to be – actually, I don't think I ever went to somebody, a couple, that were both positive – I don't ever remember that. I remember going, you know... I don't think – for some reason, there was a little more compassion. There was a little more compassion because maybe we had been – you know, maybe because at that time we hadn't been to so many funerals, memorial services, or taking people to the hospital. We weren't tired of safe sex at the time, we weren't worn out – or we were, and we just shoved it down. The stigma seemed to get bigger in the '90s, it did. There was fear – so, let's just say there was a lot of fear of the disease itself, having the disease, but there was a sense of compassion for people. In a lot of the gay community, there was a sense of compassion, and out of that compassion came AIDS Vancouver – you know, all these things that started, not only by people with HIV but by people who were HIV negative and lesbians. So, I did see that kind of compassion.

I did see people who were... I mean, we had a friend at St. Paul's hospital – this was very early '80s. He was in the hospital and a couple of us went to see him, and I remember going in there and him lying in his own feces, because nobody would change him. So, a lot of the family members would come, or the friends or the lovers, and you would see that kind of compassion, that I'm going to clean this person up and get him together. They're not going to take care of him because they're afraid. Among the Filipino population, I don't know – a lot of Filipino nurses just weren't... I remember them saying because of the Catholic religion, because they were gay or whatever, they just weren't... And at Normandy Hospital, most of the patients never got family visitors, like biological families. It was always friends, the drag queens, the people that knew them. But among them, there was this level of compassion that I'll do anything, and literally, we did everything. You know, we were helping with their shunts and cleaning up after them quite a bit because other people just wouldn't – like I said, at the hospital, they weren't doing it. They weren't doing it. As a nurse, I guess you could say, "Well, I don't want to do this," and a lot of nurses said, "I don't want to work with that, I don't want to be around it." I don't know if that's discrimination or stigma or just fear. So, where does fear and stigma – there's a line between the two of them.

There was a lot of compassion, but then as we got into the '90s, people became very tired, you know, after death, after death, after death, memorial after memorial, you became run-down. And maybe sometimes seeing people that were diagnosed and going off over the edge and just drinking themselves dead – "Well, that person's going to drink themselves to death or that person is going to do this. Why should I care? I'll go find a lover that's negative," or something like that. But yeah, I think that's a big change. There was fear but there was compassion, especially in the '80s. There was a lot of compassion among people, it was just the fear and the ignorance that people didn't know – I don't think people knew how to get it until the '90s, I really don't think. Even though we had all this safe sex stuff, I don't think people really knew.



**BK:** Was navigating safe sex a challenge back in the '80s or was that something that became a consensus in the community?

**TO:** I think it became a consensus. I don't... I think a lot of people stopped doing intercourse – basically, a lot of people stopped doing that. People wanted to have sex, of course – it's a great escape and it's a way of validating yourself and a way of dealing with shame, internalized shame. “Oh, I'm with this person, so I must be fine.” But – I've kind of lost that question.

**BK:** Oh, just around whether there was a consensus around safe sex or whether that was difficult to negotiate in some circumstances?

**TO:** I think a lot of times, for me and a lot of people, sex happened usually when you had a few drinks, or more drinks or some drugs – that became a way... And the reason that was is because the fear, you were able to separate yourself from the fear and actually have sex, whereas before, you'd be like, “Hm, I don't know, I'm scared. And are you positive? Do you have AIDS?” It wasn't even positive back then, it was “Do you have AIDS?” I'll have this alcohol and drugs and then I'll be fine. Or completely anonymous, so for instance, going to Stanley Park and having sex with an anonymous person. I wasn't into anal sex at the time. It didn't appeal to me – I just wasn't into it at the time, so that wasn't a problem. But if you had enough alcohol, if you had enough drugs, then you would. So, safe sex? Safe sex was just a lot of fear. And like I said, a lot of guys couldn't connect on safe sex. They wanted that intimacy, they wanted that – I think that even happens a lot today. They still want that connection. And you never – if a person was HIV positive, had AIDS, of course they were not desirable at all, so you didn't talk about it. You knew that if you said something that, you know, you weren't going to have any sex at all because of the stigma, so that probably created a lot more people getting HIV just because they couldn't reveal their status, you know? Yeah, so that was a problem.

I mean, I've read today a lot of men that lived through that period that might have just had safe sex or no sex because of the fear of sex, now today are trying to make up for lost time, and they're getting into the drugs. So, that's been a real – crystal meth and that have been a real problem, especially – we talked about that a lot at Dr. Peter Centre, because they repressed all their feelings for so long. And I mean, what does that do when you repress yourself sexually? What does that do to you psychologically? How does that...? I don't think it makes you feel very good about yourself, you know? You can't get really close to somebody. It's made me very difficult to get close to anybody. Like, today I had I a date for the first time, and I'll tell you, last night I started having panic attacks, and I don't know why. I think it's because of that, because for so long you attach fear with sex. It's very hard to change that, very hard to change that. The drugs and alcohol would take that away and you could be – and now they have drugs like crystal meth that can take all that shame and all that stuff, and bang, you've got a connection with somebody, mind you, artificial, but it's something. So, I think it had a big impact that way. And a lot of the safe sex was just a lot of fear, I remember back in that time. It was about scaring people into having safe sex. We were very scared, you know? Very scared. So, like I said, we'd go to the park, have anonymous sex – that seemed to be the best way to cope. But I think that still goes on today, a lot of anonymous sex, and it's probably a way to deal with the fear.

As I said, for me, sex has been the gateway to intimacy – have the sex, add ice, and then you have intimacy. When you’re used to living your life like that, it’s very difficult to change and go on a date. I mean, I’m learning to do it, but it’s still very – you want that icebreaker to know that you can have that connection, right? And so, a lot of ways that people in the ‘70s, they always talked about gay men being so promiscuous. A lot of that, like I said, that was a lot of internalized shame that when you’re with somebody, wow, that shame’s gone for that period of time – for that short period of time, it’s gone, but you want more and more of it. It’s a way of dealing with it, but the problem is you’re not dealing with the shame, so using sex as – you know? I never had enough time to deal with that. I never realized that for years and years and years. If somebody would have told me back in the ‘70s or ‘80s, maybe I wouldn’t have used sex as a way to deal with insecurities or feeling validated, if I had knew how to deal with the shame back then.

So, I think one of the things that came out of the AIDS epidemic is learning to deal with shame, because there were a lot of groups, especially for people that were HIV positive, that we have dealt with that internalized – we have brought that up, so that’s one of the positive things that came out of that. There was a group started in 1987 at St. Paul’s hospital, and I think it was the first HIV group done by Mary Petty – she’s a social worker there. So, this group came out and it was like it was two o’clock in the afternoon on Thursdays, because you have to remember at that time, people with HIV didn’t work. A lot of them were just in the hospital – that’s where they started, so they’d carry them up. So, I started going to that group, oh, in the 2000s, and that’s when I really started dealing with that internalized shame – it wasn’t until then. There was nothing to really – it didn’t feel like there was anything to help me with that. So, I would say that’s one of the big benefits of HIV, that the epidemic has had on our community. And now there’s a lot of social, a lot of support groups for people, and now of course a lot of them starting up for people my age and older living with HIV for a very long time.

**BK:** As you said earlier, a lot of people coming out of the closet back then too who might have otherwise not been eager to do so. Maybe it wasn’t a benefit at the time...

**TO:** It wasn’t. You really – to get tested in the ‘80s, you’re playing Russian Roulette. If you came back positive, boy, you could be living with a hell of a lot of psychological – you’re putting a big weight on you. But there was this idea that, oh, let’s test. I remember my doctor said, “Oh, get tested.” And I did and it was fine at the time, but what would I have done if I found out I was back then? In 1987, finding out you’re HIV positive, and having no symptoms, maybe no symptoms for years, but just living with that. Living with luggage – “How am I going to tell somebody I’m positive?” How do you live with that? Yeah, that was so difficult at that time. So, why get tested? Why? Why put yourself through that? I knew a lot of people that didn’t get tested until they found out. A lot of times it was the Kaposi’s Sarcoma where they had the – you saw a lot of that. That was very difficult. I remember going to a party – it was a Halloween party, and usually that was the parties that they would go to, people with AIDS at the time, reason being, they could wear makeup, they could wear a mask. So, Halloween was always really big because you could hide yourself and be in public, right? I remember seeing a few people – I went to one party, I remember seeing about three people there that died within weeks after that – weeks. And you know, why are you not going out with everybody else? I didn’t

understand it because it was the physical appearance was... I mean, you couldn't ask for anything worse, a worse disease for gay men, something that affected your physical appearance.

You know, even later on when the treatments came out, they still had – I mean, I had horrendous effects, so you know, it was – how do you live with that? How do you live with the fact that your appearance... I mean, literally, when I started taking the drugs early on, it changed my face. I had to have it fixed, years ago now, but at the time, I remember I looked in the mirror and I looked different, and people wondered what was wrong with me. And I went to work and people didn't recognize me. That was on treatment, the early treatment. But how does a person cope with...? And a lot of times, it was interesting because a lot of times, you would see somebody you know who had this physical change – you know, very gaunt – and you would pretend not to notice. You would sort of look, and you would pretend not to – and that's how everybody coped with it. You just didn't talk about it. You didn't want that person to feel bad of course, so you wouldn't say anything. And then through the night, you'd have a few drinks, and then somebody would point it out as they were getting drunk. They would say, "Well, why are you so gaunt?" Or "Why do you look like that?" I think it was very – you feel for that person, but a lot of times, we just totally ignored it. We tried to – you know, "You look like a million dollars," that's the way you did it. That's a huge psychological impact, physical appearance, as I said, when it's your value in the gay community. I don't know how people coped with that back then.

And then I know some people today that look pretty bad and have been like that for years and years and years, and I can understand the loneliness and anger that goes along with that. But when you're in your prime, the prime of your life, that's very difficult. I remember when I started HIV therapy, they said, "Oh, don't worry about the side effects. There's nothing that..." Dr. Montaner: "Don't be concerned about that." Holy fuck. But you know, that's something you learn to live with with HIV – you know your appearance is going to change. You know you're going to see pictures of yourself, or you know not to put pictures out of yourself, because if you have old pictures with your family, I don't put any, because they'll say, "Who's that person?" That happened to me just last Christmas, they said, "Who's that person in the photo?" "Oh, that's me." "Oh, you've changed. You don't look older, you've just changed. You don't look like the same person you were." That develops a lot of phobias and – it's like, you lose your ground, you know? You're no longer you. You're you on the inside, but on the outside, you're not reflecting who you are anymore, so that's very difficult to come to terms with.

But I'm sure back in the '80s and early '90s, I don't know if that really – I think you were more concerned that you were going to die than how you looked, maybe, a little bit more. Seeing people that always – their clothes never fit, the clothes were always too big. That was – and the cost of living with HIV at the time because you would have to always buy clothes because, you know, I knew a lot of people that had to buy clothes pretty consistently, because their body would be changing so rapidly, you know? So, that was a cost that nobody really talked about. I mean, I noticed that then at that time was when at PWA they started having a clothing – not because of people that just couldn't afford clothing, because their physical – because the change. They'd be getting thinner, they'd have that wasting disease. You never said to somebody, "Oh, you've lost weight," which a lot of people would love to hear, but you would never say that. And you knew that if somebody gay said that to you, you knew that they didn't know about the epidemic, or they were outside of the epidemic. They didn't quite – they may have lived in

Vancouver but they didn't know. They were just so – you'd be at the bar and somebody would say to somebody that had HIV or AIDS, "Oh, you've lost weight." And I knew you didn't say that, but that person, who's just your average gay man, didn't know that. So, the message wasn't really – not everybody heard the message. Not a lot of people understood it, and you didn't want to understand it. It's like, who wants to know about this? I don't want to know about that because I'm only going to get more fearful.

When my one friend was sick, I remember I had some other friends around who knew him, they were close with him, but they couldn't stand to be around, so they didn't go see him in the hospital. I remember one friend who was a good friend of his who was dying, I gave him money to go visit him, because I just wanted him to have that comfort. There was a lot of people that couldn't – I guess today, there's a lot of people that can't stand to be around somebody who's ill or sick or getting sick. I don't blame them, it's just – I guess that's just the way they are, but there was a lot of that too. Like I said, you couldn't talk to people about what you were going through. You couldn't talk to people about the loss that you were feeling, because people were just so – didn't want to hear about it, they were scared. I understand now. So, it was a very lonely – there was a level of loneliness in my life that was so deep. And I remember turning to music as a way to cope with loneliness, because it was just – even though I was around people, I felt very lonely because I couldn't express myself, I couldn't express the fear and the... Because I had taught myself to not feel. You became – I became kind of feelingless. I think that it helped me to actually be able to do my job, take care of people, because I didn't – I could take care of them, I could show compassion, but I didn't have to feel, you know? I just didn't have to feel. And I think that that became very normal – for many years that became very normal.

And then in the '90s, I really developed manic depression, and I had to start lithium and I got treated, mind you, and everything with that. But I think that living through that not expressing my feelings – the only time I really expressed myself was music. I'd listen to music and – I think I listened to a lot more folky country because it dealt with feelings, and I would walk for hours – I remember walking and walking and walking, and I had my little Walkman [laughs], and listening to that. I'd listen to songs that would make me cry and that was a way of relieving that. So, I think music was probably another – was a great way of dealing with it, because everywhere else in life, I was just trying to hide from it, but for that time when I listened to music, I could let it out, because I could relate to what the singer was singing, it could relate to my life. So, that became a way of – it became a survival – it became a survival way of coping with the loss. I don't think I even coped with loss, I think I just kind of just pushed my way through it, just waiting for the weekend or waiting for the next time I go out and have sex. That was – and people of my generation, I think that was really common. Yeah. So, what else?

**BK:** Do you remember anything else about how the government was responding?

**TO:** Well, at that time, I remember when – was it Vander Zalm – and his wife – that was the one with the headband on her...? She always had these... Yeah. Yes, I remember the government wasn't responding. There was also a lot of – ACT UP. There was a lot of fighting going on at that time, you know, to – I'll tell you, at that time, all my information about HIV and AIDS was also at the – well, it's now Positive Living, but AIDS Vancouver had a library. They've now since closed it, or it's not there anymore, and that was – they would be trying to get all the

research, because people were just dying to know more. We were just dying to know if this Japanese cucumber worked or some type of mushroom they were talking about – all these holistic treatments. So, I got a lot of information from – that’s where you got your main information. Now of course, we have the Internet and we can go all over the place, but at that time, the government wasn’t doing a lot. My friend who was getting sick, he couldn’t work of course, so we had to take him to social services, and they were really hard about it. They just – it was hard to get him the assistance – I remember that it was really hard to get him – I remember he was so sick that we had to take him there, because we had people... Like, me and his sister were handling his finances, so I guess it would be power of attorney at the time – we did power of attorney, but they wanted him there. So, I remember we had to drag him down to basically the welfare office to get him help. There wasn’t a lot of support. I never even heard of anybody getting – I don’t know when exactly they started the disability. I think he finally – my other friend finally did get it, but it took a while. Basically, you got welfare. So, you have HIV, you get welfare. What’s that? In the ‘80s, it’s not even \$500. Very hard to get an apartment.

Thank god, they found out schedule C which added a lot more money, but it was – a lot of these things were happening because of people with HIV had created this as well. So, some guy with HIV that was a lawyer found out about schedule C and how to get that, so that benefitted a lot of people because that put the income right up there. And then of course, a lot relied on Loving Spoonful for food, so that was helpful. So, I did see a lot of these services come available, mainly in the ‘90s. I mean, there was some in the ‘80s, but it was mainly in the ‘90s. But as for the government, it didn’t seem like there was a lot. My training, a lot of the training for universal – I was also working in California, I got a lot of training on universal precautions and all that stuff in California, and especially working with people with HIV, I learned a lot of that down there. So, when I came back here and doing it, it was, I had already known a lot, but they didn’t really give me a lot of information. They – when you took care of a person with HIV, they gave you a piece of paper that said universal precautions, that was it. That was it, there was no how are you dealing with a thirty-two-year-old man that’s dying? How do you cope with that or somebody that’s really angry and abusive – how do you deal with that? You know, there wasn’t a lot – the government wasn’t doing a lot. It was just universal precautions, universal precautions. The psychological part of AIDS wasn’t being addressed, it was totally the physical part of it that was being addressed, so there was that missing piece. But people with HIV sort of filled that psychological part. I think they could have given some sort of training that would – because there were other young people dying of cancer and other things, so why couldn’t they put that in there? Because you had that sexual stigma with HIV which kept, you know... I don’t even remember when they started talking about it in schools and stuff like that.

**BK:** The Vander Zalm government wasn’t very happy about that, was very resistant to that, for sure.

**TO:** Yeah. And also, on that show *The Journal* on CBC, I think that was one of the first shows on AIDS in Canada. The stigma in that and the prejudice and the fear that you – because like I said, that had a lot to do with the kids in school with hemophilia. It was just that if a kid had hemophilia, then maybe they shouldn’t be in school. So, that – what else do I remember about it?

**BK:** You said that you remembered activism was going on a little bit – ACT UP.

**TO:** ACT UP, yeah. Yeah, that was – yeah, that was big. We started seeing a lot of it in the Pride parades. It always stunned me though, I noticed in the ‘80s, in the Pride parades, there was alcohol. That’s when sponsorship came from Labatt’s and Molson’s – you’d see on the banners and you’d see in the corner of the banner, it would say Molson. They really realized there was a market, and as gay people – I mean, here’s the thing, as gay people, I think we assume that is acceptance when it was really just marketing. “Oh, we can market to these people.” But we saw it as, oh, they’re accepting us. But they didn’t do a lot in AIDS research, they weren’t there. You didn’t see them supporting – you saw them supporting bars. I worked at a gay bar and, listen, Labatt’s would do all the banners, all the – I mean, we got these chairs, all this stuff was done by liquor companies. One year, it was Viagra was huge, huge, and they had these little things all over the tables and posters – they sponsored everything, but never – it was only drug companies, you know, that really supported people with HIV, and that was later on. You know, that was much later on.

One of the things in the epidemic, in the early ‘90s, probably late ‘80s, there was a magazine, it’s still out today, called *POZ* magazine – it was out of the States, a very glossy magazine. I can’t tell you how much hope that magazine gave me. It gave me a sense of hope because you’d see somebody on the cover, they would always have little positive – they’d do treatment information – it was one of the first times I ever heard about treatment information, and you could see that there was something on the horizon, even in the very early ‘90s. I remember that there was – ‘80s, forget about it, I didn’t hear about anything – but you heard that there was something. But that magazine gave a lot of hope, and then 19- - was it ‘95? 1995, they had Magic Johnson on the cover, and they were just doing the triple combo at the time, and the cover said “Works like Magic,” these pills. It was like this ultimate hope because in the ‘80s there wasn’t hope. In the ‘90s, you started seeing hope, so that was – you had lived through this tremendous period of time where there was no hope, there was nothing. There was no hope. You knew AZT was not – I kind of knew early – we kind of knew early on because so many people had died and so many people had developed anemia. So, the ‘90s and that magazine really kind of represented hope, so I think that in a sense that that might have been a savior to me, for sure, and a lot of other people from... When you have that – it’s okay to be sick, but when you have no hope, I think you really do begin to die, begin to – psychologically, you die when you know there’s no alternative. You can accept that, but you die. I’m sure for a lot of them, it just felt like a life sentence, like a death sentence when you don’t have that hope. So, hope means a lot – hope can change everything. It changed my life and it changed a lot of people’s lives.

**BK:** And when you were diagnosed, did you have any of that sense of hope around your own diagnosis, or was there still the sense that this might be a death sentence?

**TO:** I didn’t feel it would be a death sentence – I didn’t really feel it would be a death sentence. I figured – for some reason, and I really didn’t know about all the new treatments, it was just a little while after that. I just for some reason, I didn’t feel it was going to go that way. You know, even though you heard a lot about this – I can’t remember, the Japanese cucumber was huge. I’m sure somebody will remember it, some type of cucumber. And then there was a series of other holistic things that people were doing that seemed to be giving hope. So, I could see things changing – I could see things beginning to change. Of course, there was still a lot of fear, a lot of

anxiety. I think it was just learning to cope with being HIV, you know, just learning to cope with that diagnosis. And like I said, it took me two years, and I think that's really common – it takes a lot of people a long time. I don't know about today, but I would imagine it would be still, just because – even today when it's really, diabetes is a lot harder to deal with than HIV – I imagine it's still hard because it's that sexual stigma that goes along with it. I think that's what maybe keeps that whole stigma thing alive. So, when I found out, it was – it was hard. I mean I did a lot of crying and stuff like that, but I really didn't feel... And because I had that friend who started his business – I mean, I had a lover, he was HIV negative and he still – I thought, oh my god, he still wants to be with me and he knows I'm positive. I figured, well, gees, I must be worthwhile if he still wants to be with me in spite of this. Because you thought less of yourself – you were no longer – I was no longer Tim O'Neil, I was HIV positive and then Tim, you know? You were HIV positive, not – you're not you and you happen to have HIV, you were HIV and then – because it defined who you are because it defined the end of your life or it defined how your life was going to end up, right?

I mean, my biggest fear was being in a hospital, unable to take care of myself. I don't think death was a really big fear as much as just being that, being sick. And since I have been HIV, I've only been sick once, and that was due to early HIV drugs – AZT, developed anemia, but that was really the only time in my life that I've been sick that has anything to do with HIV. So, there are a lot of people that are here today that were HIV back then that had nothing – I guess long-term non-progressors. There was a lot of that. There was also – for some reason, we kept hearing about people who tested positive and then later tested negative. I don't know what that was all about. I mean, there was a lot of controversy, but there was a lot of that. And remember, at that time, you couldn't just go online and Google, oh, you know, you had to really do a lot of research. That meant going down to the AIDS library at AIDS Vancouver to find out what you needed to know.

It was hard to lose friends. It was hard to lose my community, or people around you. You know, I mean, I've probably forgotten so many of them by now, because it's been so many years that... There was a lot of special people that I had great conversations with or I'd go sit down on Denman Street at Benjamin's having coffee all night long, and we'd talk and talk and talk, and those people are gone, and died. I think the oldest one in that period that died was forty-three. And I've lived a lifetime, literally a lifetime since that happened. I like to think that I can remember them all, but I can't. There's just so many people, you know, that brought some kind of joy to my life, that meant something to me. I don't think I have too many of those conversations like I used to have. We used to have these deep, deep, deep conversations over coffee – it was wonderful. And you know, that's something I really miss is that part. And I think for a lot of us today, we have what is known as a friendship deficit, so we have a deficit of friends, because people our age are not around, that I could have grown old with, you know? Because they were my family – not that family didn't accept me, but they were back there, and this is my life here, and when you're young, you invest in these friendships that might go on for the rest of... And two of them, remember – actually only two people, three from that period of time, where I must have known dozens and dozens of people and great connections. And as I get older, I just fear losing them in my mind, those people, I fear because they've been gone for so long, it's almost like I don't think about them, and then something comes up and maybe I'll think

about that person. But when they died, I thought this person is going to be a part of my life forever. Still, they slowly slipped away.

It meant an awful lot – there was a lot of really wonderful people that died, and not only died, but died a horrible, horrible death. I mean, like I said, my friend sitting in St. Paul’s in his own feces and no one would care for him. That was, you know... When I worked in home care, begging me – literally, the nurse would call begging me to go because they couldn’t get anybody to take care of this person – nobody would be willing to go to a person’s, you know, just to make them lunch. The friends, everybody was burnt out, that was the other thing. I remember taking care of one guy – he lived alone but all his friends were taking care of him. When I went in there, they were so appreciative of me, because they were so worn out. Taking care of a person with AIDS at that time was hard for the most part – it was very hard because you were not only dealing with the physical but the psychological part of who they were. It was draining. It drained me enormously. But as I also said, I did see compassion among lovers taking care of – friends, family, lesbians, drag queens were really, really willing to do anything. People were – I mean, in the ‘80s and that, people were terrified of even hugging someone, touching their hand. So, these were young men that were going without any kind of touch, nobody touching them, you know, unless it was a doctor with a stethoscope, something like that. So, when I would care for them, I remember touching them, and I was scared, terrified, but I did it. I was terrified to touch – that’s how much the fear – I was terrified, but I did, you know?

That really – I think another person that had a lot of impact on people at the time was Princess Di[ana]. In 1987 she hugged somebody, and that was huge. It was huge for – that was huge for me. And of course, when she died, it had a huge impact on the HIV community. Yeah, I remember a lot of lonely people – loneliness, isolation. And as I also said, I kind of ignored my own needs, emotionally and physically, because I think for a long time, I just didn’t want to live – I really didn’t want to live. There was nothing to live for – I had nothing to live for. Sex, that was dangerous now. There was just nothing. Yeah, but of course, now it’s changed. As I said, it was grim, but there was that compassion. You know, you didn’t see it on TV, but it was there. There was people that really, really cared. I don’t think we would have these AIDS organizations – I don’t think we’d be in the places we are – probably wouldn’t be here today if it wasn’t for the caring of the pioneers. You know, ACT UP did a lot, put their own life on the line.

**BK:** And the people who were looking after those folks in hospitals who weren’t being looked after in those hospitals. People were stepping into the void left by governments and medical institutions here.

**TO:** It was a huge void here. As I said, I would get calls to do home care all the time. I got so much overtime, but I could only do so much. But like I said, it left you just working and partying, because that was the only way to cope with it – the only way to cope. Sometimes you wouldn’t answer the phone – I wouldn’t answer the phone because I didn’t want to know if such and such was sick or if this person was on their way or if this person is in the hospital. It would have been nice if there was something there at that time. I think we’ve learned now, but it would have been nice if there was something for people like me that were trying to cope with what’s going on. That’s where government didn’t step in. They looked at it as completely physical, and this isn’t a physical disease – it is a physical disease, but right now, the psychological impact is



much more than the physical impact of it. At that time, of course, it was the physical impact and you didn't really think about the psychological impact. Now, it's totally changed, but at that time, it was just survival. And of course, through the years, after the epidemic, I did a lot of crying and I did a lot of dealing with it, which I said has been very helpful, and I thank god for the AIDS organizations and the support workers that really... Peer support workers – I mean, that's people with HIV that are helping other people with HIV, that became very big in the '80s, you know? So, in the '90s, like I said, when I was diagnosed, I could go down there and talk to somebody every single day if I needed to. It was that peer support. Of course, a lot of people with HIV weren't working at that time – they didn't have a regular job so they did volunteering, and they really changed – they really helped people psychologically with the illness.

I don't the government really changed until maybe the '90s. I think things were kind of homophobic – even though Vancouver is a very open city, there was a lot of homophobia around. I don't know exactly when it changed. I know of course, when Clinton came to power in the U.S., it seemed to be a real direction change in research, that type of thing, so that was a good thing. So, there was a lot of hope in the '90s, that's when I stepped in. I guess it would have been also difficult, as I know, for a lot of people that were very – you know, worked with people with AIDS, dying, that became a just sit back and stop working and become a spectator of life. So, there's a difference between living life and just being a spectator of it, and that's what I noticed a lot. Just sort of sat there and sort of just looked at life, not living it anymore. I think that was – I noticed that. There would be a lot of people walking around just like zombies, because they would have dementia or maybe from the drugs, but literally just – and a lot of them are still walking around today. You'll see it at Dr. Peter Centre today, just that stunned look, a lot of this from the tingling limbs.

**BK:** Oh yeah, neuropathy.

**TO:** Neuropathy was very common. I don't see it – I mean, it's common, but it's not that common today, but there was a lot of that. A lot of people would be walking around with a stunned look, a zombie look, just rubbing their fingers together. And then of course, a lot of people that – how did you live a life at that time? Every guy that I would see that was in home care had a shunt, so they were obviously not getting close to other people, because you had this tube hanging out of you. What kind of impact does that have on a thirty-year-old, thirty-five, forty-year-old? That would have been very hard to deal with. One thing that stunned me is that a lot of people with HIV smoked cigarettes, and some would be diagnosed and started smoking cigarettes. I guess that was a way of passing the time or coping with life, you know? So, every AIDS organization you'd go to, there'd be all this smell because they had a smoking room, but of course, smoke gets everywhere, so that was kind of an issue. What else?

**BK:** I think we've covered an awful lot. This is great because then I don't have to go through and ask too many questions – you've answered a lot of them already. I think we've talked a bit about how your perspective on HIV has changed over time, from what you thought about HIV back in the '80s to how you think about HIV in the present.

**TO:** Well, like I said, at that time, I thought of it as a medical issue. Now, I think of it as a psychological issue. So, it's – yeah, it is a physical issue but it's more psychological nowadays.

**BK:** People are told nowadays that you can live a normal lifespan if you look after yourself and you're undetectable. It does make it so different now, right?

**TO:** Yeah, so back then when it's a physical thing, it defines – like I said, it totally defines you and your days were consumed with going to the hospital, going to the doctors', going to this appointment, going there, getting help with this or that. That defines your life. You don't have time to think about the psychological parts of it, so I think that suppressed. Now, all that has come out, that now it's just, oh boy, I've got to deal with the psychological parts of it. So, I would say that's what's changed about it. Yeah.

**BK:** That makes complete sense to me. One of the other questions we always ask near the end is what advice you might have as a long-term survivor for younger generations of gay men who maybe didn't live through this period.

**TO:** Well, first of all, I don't see myself as a long-term survivor. I – you know, during the AIDS epidemic, a long-term survivor was somebody that lived with the disease for more than five years – I think it was five years, four or five years, without treatment. That we considered a survivor. But what was your question?

**BK:** That's an interesting caveat. I hadn't thought of that.

**TO:** Yeah, because a survivor – because I'm living with it, but I'm really not – I mean, I'm just taking a pill once a day. One pill, once a day. I mean, that's really nothing, right? From taking a lot of pills early on to taking just one pill a day, which kind of strikes me. I recently started a blood pressure medication, but that's a hereditary thing that affected everybody in my family in their fifties, high blood pressure, so that's really the only other thing. But I think a long-term survivor is a person that – early on, it was remarkable when you survived five years – that was remarkable. I think now they would have called that person a long-term non-progressor – I think that's sort of changed too. But I'm sorry, what was the question again?

**BK:** Just around what advice you have for younger generations who did not live through this period. Regardless of whether you consider yourself a long-term survivor, you lived through this as a caregiver as well.

**TO:** Well, I would first of all say not to fear it because I think that creates a lot of toxicity in you, emotional toxicity when you live in fear of something and it prevents you from getting close to another person. So, I would say work on the fear. Not to forget... It's kind of like the Holocaust – it's something you should know, especially if you're gay, in your history. Everybody should know what really happened. The discrimination, the stigma, the fear is really important, but also the compassion. I think it would be – I don't think a lot of people are going to want to know what we went through. I just don't feel that they want to know. I would love it if they did. I would also say safe sex doesn't work. I think what we're doing today does work, like with PrEP and that type of thing. I think I would say know your history. It's kind of important as a gay person and as a person in Canada, as a gay person in Canada, this epidemic, because it would be a shame to forget it as a lot of people try to forget the Holocaust. You know, it's really important to

remember this, because there might be another one – there might be something else that comes down the line, you know? I think also the sacrifice that people made early on in ACT UP. These people had courage, they got out there and they admitted to the world that they were HIV or had AIDS at the time. There was a lot of people with a lot of courage and not to forget them, yeah.

**BK:** And the caregivers too.

**TO:** The caregivers, yes. You can't forget the caregivers. And the lesbians, what they did for the community. A lot of the caregivers themselves were sick too, let's not forget that, because they were denied care pretty well. Being overlooked by the government, I think that that was – I don't want to hold grudges or anything, but it's important that we don't make – it's important that we remember what happened so that we don't make the same mistake again. You know, ignoring people, and I think that that could happen quite easily. The way the world is going to the far right, we don't know what's coming down the line. It would be nice – I don't know if this would ever happen but it would be nice if we had a day – I know we have December first, but if we actually had a holiday or something like that to – something to remember. I think the AIDS memorial is great, but it didn't really extend to all the other people that died. You know, there was a lot of people that died up until – many people that died in the '90s, you know, even from the medications.

**BK:** And their names aren't on there?

**TO:** No, that was just it. When they built that, and that was in 1996 or [199]5, somewhere in there, they never expanded it beyond there. My friend that died got on there, but they never really extended it beyond that. Sometimes people look at that and think, okay, well that was then, this is now, so why should...? Maybe they will forget. Maybe thirty years down the line – why would you remember a group of people that are all gone? At some point, we'll all be gone, and most people who lived through the epidemic in twenty, thirty years – well, thirty, forty years maybe. It would be nice if that was remembered, you know? I'd also just remind people of the compassion, like I said, the compassion that came out from the caregivers who really got into the trenches, who were cleaning people up constantly. Because diarrhea was huge. It wasn't uncommon to smell it in bars, it wasn't uncommon to see people with dirty pants who crapped themselves walking down the street – that wasn't uncommon. And I know a lot of people who had a lot of compassion for people like that. They would help them – you know, they would help these people. So, I wouldn't want them to forget that.

**BK:** We're certainly trying to think through, at a project level, how we can better remember as a community the people who have passed on but also how we responded as a community, and how this is important for us to remember as a community. That's a difficult one.

**TO:** Well, like I said, I think the emotional support wasn't really there for a lot of people. I really don't know if it's – I mean, they just in the last three years or so, they started this group for fifty-five plus, so a lot of people that got treatment, a lot of it was, you know, you've got treatment, what more do you need? That's basically it. You're going to live. Take your pills, and you'll be fine. A lot of people that lived through that were psychologically devastated, so how can you just be fine? I was lucky enough that I just figured out that I had to do some work. I read books and

sought out therapy, and it was very hard for a very long time. Not until about 2010 did I really feel like I kind of dealt with a lot of those issues, so that was twenty years after it happened. It would be nice to know that there's that support for people, the caregivers, if, god forbid, we go through something like that again. But know your history, don't fear it, and don't blame somebody for getting it. You know, even today, it must be difficult if a person becomes – a younger gay man becomes positive nowadays, it must be difficult because it could be very lonely because of PrEP – “Why would you get that? How could you possibly get that when you can prevent it?” For whatever reason, I feel for those people, because they might be stigmatized in their own community, because of that. I think we need a lot of psychological work in our community too. I'd also tell somebody that physical appearance is not important. Don't put that much into it. We really fussed over our appearance back then a great deal – a waste of time.

**BK:** We could stand to be a little bit less superficial as a community?

**TO:** A little? [Laughs] It would be nice. It's hard to find though – it's really hard to find. A lot of people who lived through that period of time have really not changed. I know a lot of guys that – I worked at the Pumpjack and I know a lot of older guys with HIV that go there and still live in that same life but are going home isolated and alone, and it's not meaningful. And like I said, a lot of them my age now have a deficit of friends – they lost and maybe don't have the ability nowadays to have a closeness with other people, to have a connection. So, that's why I'm so supportive of this group, because there are people there that don't talk to anybody all week, and they go there once, or some people who are in jobs, they're working, but they're still not close with anybody, you know?

**BK:** Yeah, I'm so glad that that group exists.

**TO:** Yeah, we need more like that, because we have an aging population. And learning to age with HIV, that takes time to learn that too – how to take care of yourself and eat healthy and do all the necessary things. And a lot of people don't do that too, a lot of them just drink and that. Like I said, that escapism that I was doing in that period of time, I was able to stop that when I came to terms with things, when I learned things, but I know a lot of people that never got beyond that. They might not be having as much sex, but they're using the alcohol and the drugs to still escape from the feelings they might have had back then – survivor's guilt, whatever, they're still... That needs to be addressed, I think, as our group is doing that, but it still needs a lot more.

**BK:** Absolutely.

**TO:** It would be nice to take away the drugs and alcohol out of sex, but how do you do that? To have people just be able to deal – I think this generation, also, younger people nowadays have an ability to deal with their problems with intimacy more so than we did. There was nowhere to turn for fear of intimacy. Where did you turn for that? There was nothing. That's probably one of the reasons the AIDS epidemic was so bad too because, like I said, I was always looking for validation through sex because I never had anything else – there wasn't anything else around. I cried a lot back then. I remember crying a lot. I think I cried so much – that was a big part of my life. And I guess one of the other things I want to say probably is I lived with a sense of fight or

flight – I guess that that was a really common – that anxiety became really, really, common occurrence, because you didn't know who was going to get sick, you didn't know who was going to die, you didn't know what was going to happen. You know, I couldn't – you didn't know – like I said, it was living in that fear, and that played on me for many, many years, right up to the 2000s. I couldn't just let go, relax, be at peace – even though you tried to go to meditation groups, that sort of thing, you never could. There was this underlying fear. It's like if you watch CNN, you see the scroll on the bottom, it's like that's always going on, this is always going on – this person might get sick. Can I go away this weekend? Well, this person might die. So, you always lived with that, so living in that flight or fight, that plays a lot on you, you know?

**BK:** It's not the way that we're supposed to live our day-to-day lives.

**TO:** No, but it also explains the drive to do drugs and have sex, because that was the only way to relieve that – really, the only thing that relieved that. Otherwise, you just woke up and you lived with it every day – day after day after day. There was nothing to deal with that, that's what makes me kind of angry about it, is why wasn't there somewhere, why wasn't there anything to help us cope with what we were living with? It's like being in a prison or like the Holocaust. It's like being in that all the time. I think for a while, when I went away, I went on a holiday, and felt, oh, I'm not thinking about that. And it would actually take me a little while to think, oh, I'm not thinking about that. Otherwise, it's always there, like that scroll, it's always there. It never goes away, it wasn't really, then around 2000, 2002, it kind of went away. That is when it really stopped. So, even though there was treatment for HIV, you know, they weren't the miracle drugs, because the side effects were horrendous, horrendous for a lot of people. There was a little more support but still it was difficult. But in the end, I'm now thankful that I lived through it, you know? I mean, I really don't have much choice, but I'd rather look at it as something that has been a benefit in my life rather than a hindrance of any kind. I'm glad I lived through it and I'm glad I'm able to see the positive things that came out of it. I'm really happy to see that people can prevent it – you never thought anything like that would ever happen. You never in your dreams, in a million years, would ever happen, that you can actually prevent it, wow, and treat it, and just take a pill a day. Sometimes the guilt comes back, because I think of my friends who had to take twenty million pills and they didn't get any help.

**BK:** Well, unless you have anything else to add, I think we've really covered a lot of ground.

**TO:** Are you sure?

**BK:** Yeah, you've touched on a lot.

**TO:** Oh good. Okay.

**BK:** So, I just want to say thank you. I really appreciate the opportunity to get to hear about your experiences.

**TO:** I am so thankful that you are doing this, because this is something that has been needed to be done, especially from a younger perspective that didn't really live it, it's so important. And I hope I was able to convey what it was like. I hope I'm able to help other people to know what I

went through, and maybe it can help somebody else, or maybe just have that history documented. It would be a shame if we go twenty years from now, or thirty years, forty years from now, and they go, “Well, what was that, what was AIDS?” when we’re all gone. I would hate the thought of that, just because I’m afraid of that happening again. Yeah. I can’t think of anything else to add. [Laughs]

**BK:** Well, like I said, we’ve covered a lot. I really am very grateful. So, thank you so much.

**TO:** No, thank you for doing this. It was great.

**BK:** So, I’ll just stop this.