“HIV in My Day” Interview 3

October 16, 2017
Interviewee: Nazim Murji (NM); Interviewer: Robert Ablenas (RA)

RA: Thank you for consenting to be a part of this project and for sharing your knowledge of the early days of the epidemic in Vancouver. Just to get started, would you identify yourself as a gay man, queer man, or – in general – a caregiver for persons during the early days of the epidemic?

NM: Um… Gay and in the early days of the epidemic, yeah, I was a caregiver.

RA: Okay, alright. So, just to start out what – could you just share your experience of when you first came out.

NM: Well, first came out... There’s not a – I can't say that there was a time I came out, it was kind of a gradual process. I first came out to people who were closest to me or who mattered to me and actually it's gone back and forth because of the – of the AIDS epidemic of the time and the stigma attached to it and the stigma attached to gay men at the time. I didn't go into the closet but I kind of did not make myself publicly as much, sort of, known about my lifestyle at the time. So, it's kind of been a – quite a journey of, you know, going up and down, but – but now I'm out to more than I've ever been so... yeah.

RA: Was that up and down in Vancouver? How long have you actually been in Vancouver?

NM: I have been in Vancouver since ’75 and then I did go – I am a nurse, I was a nurse – and I moved to Seattle for a couple of years because I was going – I was going to school there plus my partner at the time was American and lived down there. So, I was down there living with him and going to school.

RA: When did you come back to Vancouver?

NM: Well, because he… So, I tested in July ’87 and he got full-blown AIDS that year in November ’87 and I looked after him, and then I had to come back to Vancouver because of financial reasons – I had to get back to work and… So, I came in November of ’88 – I came back – and he passed away in March of ’89.

RA: You were in Vancouver and then you went to Seattle…

NM: Right.

RA: …and back to Vancouver, so you actually have two different – you have two snapshots of life in Vancouver from different times. Any observations regarding earlier versus when you came back?

NM: Yeah. Earlier it was – when I lived here before moving to Seattle, I remember even in the late 70's actually gotten [sic] beaten up walking on Davie Street. Yeah, I was actually walking with my partner and just by where the Starbucks is now on Davie and Thurlow, in that vicinity, I got sort of – nothing that – I was injured badly but I was attacked. And then – and then I moved to Seattle and I lived way out in suburbia in Seattle so I was not in sort of – in the gay ghetto. But coming back… it was hard because at that time I was very healthy, though I was positive, and seeing my partner – as you know at that time it was a horrible death for anybody who had full-blown AIDS. And even coming here I noticed people I had known before who were HIV positive or had AIDS, and to see the deterioration of just their physical appearance was quite shocking. So, that was one kind of noticeable difference that I saw from before and after.

RA: Were you seeing any of that actually in Seattle before you came to Vancouver?

NM: No, and the reason was because I was quite removed from the gay part of Seattle – you know, Capitol Hill where the gay community – it was like the West End here. We didn't reside in that area so I didn't see as much, 'cause I was busy with school and we lived out close to the airport so there's not as much exposure to the gay community at the time. But I was of course with my partner who I saw deteriorate.

RA: Okay… Any other observations about the community before you went to Seattle and when you came back as well? You mentioned the violence that happened to you.

NM: Yeah.

RA: Was that an isolated incident? What time of day was it? Were there other people around?

NM: It was an isolated in- - I'd never experienced anything like it before or since. But it was daylight, so likely the evening 'cause we had kind of gone out to dinner and were just walking to the restaurant, and that's when it happened. So…

RA: Okay. Any other observations about community at that time, before the epidemic?

NM: Um… Nothing that stands out, no. Nothing significant, or…

RA: Okay. When did you first hear about AIDS or HIV?

NM: Actually, when I was in Seattle. 'Cause I moved there in 1984, '85, something like that – '84 I believe, yes. And it was on the news quite a bit at the time – the "gay disease," as it was called – and it was scary at that time, not knowing, because I had been with my partner since '82, so we'd been together for two years at the time. We didn't know if we had, prior to our relationship, caught the bug or not, so it was scary – it was very scary. It was like – it was every time, that, like, I coughed, I thought, "Oh, is this it? This is when it is going to happen, you know. Is he going to develop something?" It was always scary. And then when the test was first made available, and that was around July of '87 or maybe a little bit before, but then I thought, "Ok, I can't live in this fear of not knowing any more. I need to get myself tested." And so, I did.

RA: You mentioned hearing about things on the news with the test. Is testing something they mentioned in the news, or…? Like, what kind of things were you hearing on the news?

NM: On the news, just hearing how gay men were dying and just seeing pictures, or you know, of young men in hospital beds. It was – it was a scary time, because not knowing – could I be that? And then, like I said, when the test was… I can't remember if I heard on the news or something, but I did find out that testing was available. So, that's when I went and all that. So yeah.

RA: Okay. Were there any other sources of information for finding out what was going on or what's available?

NM: No, no. The only thing was through the media – like on the news and stuff. I didn't – I didn't access any of the kind of support or didn't... didn't, you know reach out.

RA: That's in Seattle?

NM: In Seattle, yes.

RA: So, what about when you came to Vancouver?

NM: Well, when I came back to Vancouver, initially it was really difficult time to leave my partner there. But I had to, because he couldn't work anymore, of course, and I was the one that was supporting him. And the way we had budgeted, like, that I would graduate and then start to work and all that, and then this came. So, it was hard to continue with school and he couldn't work, so I had to support him, so I needed to work. So, I came back and started – started working again, here. So, it was hard. So, I drove back and forth between Seattle like I was going into downtown or something, you know - like I had to go down all the time to go to look after him. So, work here, drive down here, be with him, come back, it was just… So, that was from November '88 till he passed away in '89 of March. So, that was a few months, but still it was quite a difficult time, to leave him alone in that state.

RA: Was any of that time in Vancouver or was it all in Seattle still?

NM: Looking after him?

RA: Up until 1989, did he come at all to Vancouver?

NM: No. He was physically not able to.

RA: Okay. What was your first reaction when both of you were hearing about AIDS in the media? I think you've said a bit about this already, just any other…?

NM: Well, it was – it was, yeah – a lot of mixed emotions at the time when we were first hearing about it. It was like, you know – well both of us thought, "Well, could it be us? We don't know." And it was – it was a fearful time because we didn't know. And it was just – it was a scary time, that's what it was, basically, because there was not a lot of information and there was, of course, a lot of stigma. And we just didn't know how – how it would end up being. And then when we did realize that we were positive, it was even more scary. And then, like, from July – and he became ill around October, so within a very short period after we tested that he became ill. So…

RA: How did – you know, the first part, when it's scary – before either of you were tested…

NM: Yeah.

RA: How did you handle that? Was there anything to help with that?

NM: No. It was just – it was just us. Like, we didn't share it with anybody, so it was just – as far as dealing with it, it was just the two of us were each other's support at the time.

RA: When it was scary – I'm getting from you that part of that was not knowing what's going on, and then being diagnosed, still maybe not knowing what needs to be done. So, how did some of the latter – some of the scary once you were diagnosed – gets addressed, or did it?

NM: Not really, because it was – there were so many uncertainties at the time because, I don't know. I mean, there were all kinds of [undecipherable] that people – you know, that said, "Oh, people could have been tested, you know – or converted, seroconverted, ten years ago but there would be no sign of it and they wouldn't know." And people have survived, not knowing, so there was a lot of this stuff, but there was no factual stuff. So, this speculation about, you know – people could have become HIV positive for five, six years and not know that they were positive because they were so healthy. So, could I be one of those people that would never get sick, or would I be one of those people that would get sick in the next year or so? And then when my partner became ill within a few months of being tested, I thought, "Well, mine is just around the corner. It's going to happen anytime – it's going to happen anytime, yeah." So, it was – it was – you just lived day-to-day and hoping, you know – thinking that it's going to hit me anytime.

RA: Okay. Did you – you started getting factual stuff, is that right?

NM: Yes.

RA: Did anything stand out for you as making a difference for you or making any kind of mark on you in terms of the factual stuff as that became available to you?

NM: Well, at that time, the factual stuff was mostly to do with – that death is going to be inevitable, you know. So, it's going to happen because there is no cure for it. Actually, my partner did, at that time, start on AZT, which was horrible. He just did not take that well. It was not physically – it didn't agree with him at all. He was very sick with it. So, it was kind of, okay, there is this supposed drug that will help with the progression of HIV, or something like that, and yet I could see that it wasn't working for him. So, I kind of felt that, okay, there isn't anything if this happens to me – and when it – not if, it was when. There's nothing that's going to stop this. And I just – like I said, I just lived day-to-day, wondering is it going to be tomorrow? Is it going to be next week? Is it going to hit me? And it was this constant fear of the unknown.

RA: Places you would find things out, and maybe it's just hearing things about AZT or these other things you've mentioned – any sources stand out in any way for you? Any that you remember?

NM: No, and sometimes I have regretted not doing that, because there was – you know, there was stigma there. And there's a self-imposed stigma, and I think for me, I think besides stigma out there, there was a lot of self-imposed – like, I was afraid, you know? I don't want anybody to find out. If I go to any kind of support group or anything like that, there would be people there that did not know about me, and they would find out – and I don't want that. I don't know. Because I was a nurse and worked in the health field, then I thought, maybe there are caregivers there who would find out. And so, it was – yeah. It was this self-imposed stigma, that I thought, "No, I can't go out there, because there might be people out there who find out, and I don't want that."

RA: So, further out from you and your partner, there's, say, the gay community. There's also the public at large. I'm just wondering about your sense of perceptions within the gay community regarding people infected with HIV or with AIDS. And maybe also the broader community at large in the Vancouver area.

NM: In what aspect? As far as support or…?

RA: In terms of their perceptions of AIDS and HIV.

NM: Within the gay community, I think there was a sense of community. I think there was a greater sense of community at the time because people had to come together. The broader community – the mainstream community – I think there was this… "it's because of your risky behaviour that you have this." That "You were reckless with, you know, your sexual activities, and so, you know, there's always a consequence of recklessness and this is the consequence, what's happened." And that was – partly contributed to my self-imposed stigma, that I thought, "It is. Had I not done what I did, I would not have this."

RA: Let's stick with the outward community that's contributing to the stigma, right? Do any things stand out for you that maybe was reinforcing that feeling for you, or…? Just any experience of people out there, not necessarily in the gay community, contributing to your feeling stigmatized?

NM: Yes. I – and still am – have a strong faith. So, my faith community at that time said that – they were supportive, they didn't shun me – but said that, "What you did was a sin and there's consequences for sin." And so, I had to accept that even within myself. I thought, "Yeah, that's what it is, 'cause I did something that was against God's will and now I'm paying for it." So, it was – like, I wasn't shunned. Like, I wasn't kicked out of the community – of my faith community. They were supportive – actually quite supportive. But it was – that was there, that you know, okay, we all do things that are not right and we always have to suffer the consequences of our wrongdoings, and this is yours.

RA: Going to the support, you mentioned in the gay community that there was a sense of support. What did that look like?

NM: I actually – I didn't – I looked into some of the support groups and I talked to people who I knew attended them, and I asked a couple of guys that I knew. And I said, "Do you belong to part of this support group?" And I said, "How is it?" So [they said], "I would never go." And I said, "Why not?" And he says, "Because it is the most depressing place to be because everybody is talking about what ails them. You know, I'm on this medication, or I'm taking this, you know, natural medicine, and all that, and it has this side effect." And he says, "You just sit there and it's just pain, pain, pain, pain." And he says, "You just – after you're done with it, you don't come out of it – you think, okay, this is what's going on and it's going to hit me also." So, I was kind of, not discouraged, but I kind of felt I don't want to be in that kind of environment, so I didn't pursue it in any way. I did volunteer for Loving Spoonful and – so, I was delivering meals. But it was also – seeing… People who needed those meals, of course, were not physically well, so seeing that was also a constant reminder of what is to come.

RA: You started and – my next question was going to be what other types of support were out there. So, you know, you mentioned one area of support, where you found it depressing…

NM: Yes.

RA: … because of the people there. The Loving Spoonful work – that's going to people's homes, right? So, that's very intimate and you're seeing someone's circumstances in just – for what they really are. It's not abstract; this is very real. Other types – you mentioned support, the community being supportive. Anything else that comes to mind that is, in general, just somehow the community helping those who are living with HIV, living with AIDS, or coping with loved ones, even?

NM: You mean within the gay community?

RA: Still within the gay community, yeah.

NM: I actually would not be the best person to talk about that, because I removed myself from it, and… One, I was more involved for the first few months looking after my partner. And then – and then I was dealing with the loss of my partner. So, it was a combination of many things – losing him and also… having to live with the uncertainty. So, I – for whatever reason at the time, I did not seek out any support. I just kind of dealt with it within myself, and… I would not advise anybody to do that – it was horrible – but at that time, that's how I dealt with it. Yeah.

RA: Okay. You shared a bit about your identity – the religious aspect of your identity. Any – any observations or memories about all the many different things that define you – your identity – effecting in any way your response to the epidemic? Is there anything inherent in your identity that effected your response or how you were feeling about the epidemic? Obviously, there was the issues with your partner – that's very personal – but any other aspects of your identity? You mentioned religion. Just anything that defines you effecting your response?

NM: Um… I'm not sure I'm quite understanding the question, but if I am understanding it correctly – then correct me if I'm not… There is another layer of – of stigma… I don't know, you may want to edit this because it may not be pertinent. So, the skin colour that you see on me is not the one I was born with. I used to be dark-skinned and I have Vitiligo, which is the same condition that Michael Jackson had. So, over the last ten years, I have lost all of my pigment and become what it is now. Being a darker-skinned person within the gay community was a second-class citizen. So that too, I was always aware that I belong and yet I am different. So, personally, as far as my journey, it was a combination of things. It was… Within my community I felt like a second-class citizen because I was gay, and then within the gay community, where I would feel that I should – I'm part of this community but yet I was – there was one aspect of me that was not mainstream within the gay community. So, there was, sort of, this layer of – you know. And at the time I felt it and I – and I kind of thought, "Oh, it's just me." But as I have lost my pigment and become the colour that I am now, I have even more realized that there is white privilege within the community. The way I was treated as a dark-skinned person and the way I am treated as a lighter-skinned person – yes, there's a difference. It's not obvious and out there – very subtle – but it's there.

RA: Remind me, were people aware that you were diagnosed with HIV within the community or…?

NM: Uh… I – there were people that I knew personally and were good friends that – yes, they knew.

RA: Were they aware of your partner's circumstances?

NM: Yes.

RA: Any sense of whatever you were describing about being treated as – did you say "second-class citizen?" Any sense of that being softened a bit or less when they recognized the other circumstances that you were dealing with at the time?

NM: Yeah, so you know. It's… When I say that second – I mean, nobody was ever rude to me or… it wasn't that. But there is a very – it's very subtle, that. And I think it's because, as human beings, we're kind of tribal, and so there is this ease, I believe, that somebody who looks like you – there's a sense – there's a different way of being with that, or interacting with that person. When the person looks different than you, then you, kind of, have this… And I don't mean that the person that doesn't look like me is a racist or a bigot, but there's this – there is a difference. And I – all I can say is, and my situation is kind of unique because I've been on both sides, you know, so to speak – as a darker-skinned person and a lighter one – and I've noticed, "Oh wow, this didn't happen before." So, there is – there is a difference. And I'm not saying that the gay community is a racist community or anything like that, but there is a difference, definitely difference. I walk into a bar or something – it's there, you know. There's a difference. And I cannot put into words, that, "Oh, this is what they do and that's how it's different than what it was before." But there is energy or non-verbal… behaviour that kind of makes you feel, uh, this is a bit different than how it used to be. So, I'm not trying to demonize people that, you know – I'm just saying that there's a difference, definitely. Even like – going to the Bay shopping, it's different than it used to be, yeah.

RA: And I don't want to belabor the question, so there's the religious side of you; there's another side of you that, regardless of outward appearance, you're a dark-skinned man and all that comes with that, right? Anything else? Just wondering.

NM: No. I mean, nothing that defined me, yeah. There was nothing like that, you know.

RA: Okay, thank-you for that. You've told us how the epidemic manifested itself in your personal life, with your partner, for example. In any other ways?

NM: Manifested in myself as in…?

RA: Well, in your personal life, effecting you in some way. Say, possibly your relationship with other friends, other people in the community…

NM: Yeah. I did not – I did not get involved in any other relationship after my partner died for the longest time – for… when I say long, I'm talking about years. Partly because I was afraid that I would – well, afraid that, I thought, you know, "Okay, how long am I going to live?" And so, if I get involved in something and invest in a relationship, for how long? And so, I didn't – that plus – I was not ready to publicly meet somebody – well, meet somebody in public and tell them that I was positive. No way – not knowing how that would go. So, I sort of – I kind of went into hiding for many, many years – just on my own, dealing with this with very little support, and did not get involved. And so, that did stop me from getting involved in another relationship.

RA: Did anybody try to get involved in a relationship with you?

NM: Yes. And I did not go there because I was not ready to disclose my status. So, I – there would – I met guys who were interested, but I did not encourage it or pursue it, because I knew that, if I did, then I would have to disclose this, and I was not ready.

RA: And sex as well?

NM: Yes. I would have made a good priest… [laughs]… for all those years. Yeah, it's like I – I was – I did not have sex for many years. Until I would say – I would say from after my partner died in '89, about ten years. I did not get involved in any kind of relationship or sexual relationship.

RA: Some of that related to stigma?

NM: Um… Not necessarily. I think it was to do with – I just – I didn't know what was going to – like, when I was going to get ill. And just was not ready for that, so I just thought, okay. It was almost like waiting to die. Yeah.

RA: Okay. Really zoomed in at a personal level: part of not getting – not pursuing a relationship is – let's call that a behaviour change, right? Would there have been – what other behaviour changes would there have been during the epidemic for you?

NM: For me, it was – like I said that I am a person of faith and, during those times, as much as I kind of was told and did kind of feel that my condition was the consequences of my wrong-doing or my reckless behaviour… And, as I said, I didn't seek out a lot of support from others, so there was this – within me, the spirit… I will use that, which – where I found comfort and support. And so, in – in a lot of ways, it made my faith even stronger. Even though people told me that I was "Oh, you got what you deserved" type of thing – because I've always been and until today, that my faith is not based on another person. And people can – my faith is not man-made. So, even though people may mistreat or say the wrong thing or whatever, I'm not going to allow that to – to taint or tarnish my faith. So, yeah. I grew even closer to God and felt stronger spiritually than I ever did before, living through a hardship like that.

RA: Okay. There's the spiritual; there's putting the brakes on pursuing a relationship; there's not turning too much to outside support, you said. Was there any out there that you could see though if did want it?

NM: Was there any…?

RA: You weren't – you said you weren't turning to outside support, but did you have a sense that if you did want it or change your mind or need it, it was out there? And where would that be, the support?

NM: Where would the support be?

RA: Yeah.

NM: Well, it would be within the gay community. Like, I knew of different groups or organizations that were out there, that were available for me if I did pursue it. At that time, I chose not to, and – and I think, you know, in hindsight when I look back and think that a lot of that was self-imposed. Nobody told me not to do it. I just went to this state – possibly it's because I was dealing with – emotionally, with so many things, and maybe I was in this cloud and I couldn't see clearly, and I just dealt with it that way. Now, when I look back, I thought, "No, that was not the best thing." But maybe it made me stronger. I don't know. Yeah.

RA: Okay, so thinking about other behaviour changes, as well. You mentioned – you used the language you would have made a good Catholic priest, and I misread that at first…

NM: [laughs] It could be, that's right.

RA: … But anyhow. You actually chose not to be sexually active for several years. Is there anything else? Those are all big things and they're all connected to this. Anything else come to mind?

NM: It didn't change, but the impact that it had on me – one was my – my relationship with my family, with my parents. We're a close-knit, tight-knit family. So, I – and I'm the only son. I have twin sisters, but within our culture, it's the son that carried the family name and all that. And I knew that that was not going to happen, and now I knew it was definitely not going to happen. And so, I lived with that sense of disappointing – that I… Plus, knowing that death was inevitable, that it was going to come sooner than later, I was always worried about them, because – like I said – we're a very tight-knit, close family, so I knew the impact that would have on them. It really – it really made me sad that I was going to – that I disappointed them – and now I'm going to hurt them, because when I go, it will be devastating for them.

RA: Okay, you had these feelings with respect to your relationship with your family.

NM: Yeah.

RA: Did that effect how you interacted with them?

NM: Yes, I believe so. It did, because I – I just didn't know how much time I had with them. And so, I – I was healthy, at the time. I was fine. There was nothing wrong with me. I was still working, you know. And because I had sort of cut myself off socially from everything, I spent more time with them, travelled with them, knowing that when I leave, it will be with all of these good memories that they will have. Yeah, I was – yeah, I think I got even closer than I was before, and we were very close.

RA: Okay. Don't be offended if I ask – did you do drugs and did the epidemic effect any of that?

NM: Thankfully, I never have gone – I've never done that. Because it was – there was a lot of it going on then, and many HIV positive people were dealing with the fear and all that, and did that. It just – it didn't go there for me, thankfully. It would have been very easy, but I didn't.

RA: Aside from with your partner, did you end up finding yourself providing care to anyone else within the community?

NM: I did visit and spend time, but not – I was not the primary caregiver. I was just, sort of, a friend who knew somebody who had HIV or had full-blown AIDS, and I would go and visit and spend time with them. But I was not completely involved in their care.

RA: When you did the Loving Spoonful meal – dropping off the meals – was there some of that in there, beyond just, "Here's the meal"…?

NM: The Loving Spoonful at the time – what was happening was… There were a lot of gay men who were involved in that, in volunteering in the delivery of meals and stuff. So, they mostly picked the West End and within the gay community to deliver the meals. So, when I came in the picture and began to volunteer, all those positions were filled. So, I got the – the undesirable place. Most people didn't want to go there, but to me it didn't matter, so I got the Downtown Eastside. So, I would go into those rooming houses on Hastings and Powell and Cordova and deliver there. So, it was – 95 percent of the people that I came in contact with were drug addicts and had HIV because of drug use.

RA: You – were you then providing significant support then outside of the gay community but for persons with AIDS?

NM: No. That was my extent of, sort of, contact with the – with the HIV population in looking after just delivering meals. And there was – because of their state of mind and the environment that they lived in, I – it was not a place for me that I could sit and visit, or anything, so… Basic level of delivering meals and then maybe say a few words, but nothing too significant, partly because of their drug use. They were not coherent or couldn't interact.

RA: Thinking of other organized efforts – whatever organization was putting on the support groups you mentioned, the Loving Spoonful… Anything else that you might have been involved in, even briefly, or did you have any friends involved in any forms of support within the community, and maybe even vicariously…?

NM: Yeah. I actually – the reason that I got involved with Loving Spoonful is because a female friend was doing it. And mostly for females, they gave the West End for delivery – they didn't want women to go into those neighbourhoods. So, she was looking after a gay man and delivering, and she spent a lot of time with him. She would just not – she would sort of – she would go and deliver the meals last to him so that she didn't have to go anywhere else and spend a couple hours with him every time that she delivered. So, I knew – I never met the guy that she looked after, but I knew about – she talked about this person without disclosing any more information. And then he died – he didn't survive.

RA: You've seen the community from the late-eighties – sorry, 1988-ish, you said? When did you come back?

NM: '88.

RA: '88. So, from then through to the present, you've seen the community evolve from the early days of the epidemic to various interventions with progressively greater success in supporting people. Any thoughts on what we've learned – what the community itself has learned from all of this?

NM: I actually have had many conversations with younger gay men. They have no idea. They have no clue of what happened then, and how far we've come from what it was. Yeah, I have very close young gay men who are friends, and I talk about it and they say, "Wow." They don't even bother themselves to get to know about what it was and what it, in many aspects – not just HIV and treatment and how far we've come – but even just gay rights. Everything else… They're so far removed from it and it's beyond their realm of – of what it was like. Many are interested and I will share articles or books, or whatever, that I've read that talk about that period. And they kind of go, "Wow." And this is because I told them. There are young gay men out there that have… Yeah… There's not much, I don't think, interest. It's because it doesn't impact them today.

RA: What about for, maybe not younger generation, but maybe some people that were just really isolated from all of this who could be not millennials or generations or whatever…

NM: Yeah, so I have – I have a good friend who is younger than I am, but old enough to have gone through that period of time. He recently, within the last four or five years, became positive. Before – and we've been friends for many years and he knew that I was positive – when we would talk about this, like, he – very little education about HIV. Like, he knew how it was transmitted and knew about safe sex and all that, but very little about, you know… I talk about, you know, "My viral load is this. And it's gone – and this is how it is on this medication." And he was like, "Yeah, but I'm negative so it doesn't – I'm not too…" It's something that he didn't get involved in. And he's like a man in his fifties and yet – it was almost like, "Yeah, it doesn't affect me." But now that he's positive, it's very different.

RA: What lesson do you have, actually – just with respect to having seen what you've seen and lived what you've lived?

NM: What lesson?

RA: Any lessons for you? Anything that surprised you – that changed your thinking at all?

NM: Not surprised me, but has actually – it is encouraging and I'm glad to see the changes in the attitude of people – and even mainstream community – as far as HIV is… I can't cough and somebody can get it, type of thing, or drinking from the same glass of water. I think that is – that is positive, the changes that have come about. And there is significantly – the stigma. Like, I feel I have no problems if it comes out – I don't wear a label saying I'm HIV positive – but if it comes up, I don't hesitate to say that I'm HIV positive. It doesn't – I don't hold back. And partly because I – actually, it hasn't happened in recent years because I've been rejected or people have treated me differently because of it. It's like somebody saying they have diabetes – for me, personally, that's what's happened. There's been quite a change.

RA: Wondering when you became comfortable and, even despite a sense of stigma, feeling free to actually say for yourself. Any idea of…?

NM: Around when? I would say early-2000 – 2001, '2, when it became… I have done other volunteer relief work overseas. I went with a medical team to Somalia in '94 when I knew I was HIV positive and – but nobody else did. And then, in 2001, I went to Afghanistan amidst – in the thick of war – and the organization I went with knew I was positive. And yet there was no – it was fine.

RA: International organizations of some sort?

NM: Yeah. Yeah, there was no – no hesitation of saying, "We can't let you go because of your status." But at that time, treatment was available of course, so I was fine.

RA: What about – where do you see – what do you notice about healthcare providers now versus then? What do they seem to have learned? What are they doing better? What might they be doing worse… anyhow? What's your assessment of healthcare now versus where it was then? In essence, what have they learned and what does that look like for you?

NM: So, I did have full-blown AIDS in – I became ill after I got back from Somalia. And I – I was – for two years, almost, I was bedridden – almost two-and-a-half years – eighty-four pounds, CD4 count of zero, and viral load was off the charts. So, I was very ill and had several admissions to St. Paul's – in and out. Caregivers – they were so good, so supportive – they were excellent. They were really – this was the HIV unit at St. Paul's. They were really good. So, my experience with healthcare providers has always been positive. I haven't had a bad experience where somebody has looked at me differently or treated me differently because of my HIV status. And obviously they all would know that I'm positive, whether – to the rest of the world, I was hiding, but to them, of course, I couldn't. So, it was – I've not had a bad experience with the healthcare providers. The physicians that I've had to deal with – yeah, it's been very good.

RA: Some of the healthcare people behind the scenes try – they're doing their best to make sure there's no new infections, and you were even just telling us about how a friend, who just four years ago became infected with HIV. Do you have any advice just based on all of your lived experience – Vancouver, maybe Seattle? For the healthcare providers, how can they more effectively cut down on the number of new infections? You even also mentioned these young kids that, you know – who you're in conversations with, friendships with. If they have no idea, they're at risk of infection. So, just what advice would you have for healthcare providers, maybe, in terms of just trying to prevent new infections.

NM: I think it's – because the face of AIDS has changed so much, that people don't see it like it used to be, especially young people now. And all my young friends who I – who I talk to and I always say that, "You see that I'm very fit and I'm very healthy and there is nothing wrong with me – all that." But, I said, "You do not want this." And I talk about my past experience and even present, I said, "Yeah, you will not die from it necessarily, because of the treatments that are available, but if you're twenty-five, do you want to be popping pills for the rest of your life, and going in for bloodwork every three months, and seeing, well, what is it, and doctor's visits and all that?" I said, "Do you want to start this at this age?" Because there's still no cure for it. So, I think the – the face of AIDS has changed, but the new face still has to be put out there – the reality of the face is… yeah. People are HIV, don't look any different. They're fine and all that, but it's still there – it's not gone. So, that would be my – I would say, that's what my advice to my younger friends has been.

RA: Have you shared that advice and did you get any reaction to it?

NM: Shared that advice with the young?

RA: To the young themselves.

NM: Oh, yes. Yeah. That's one of the very first things that I share, because I see this twenty-two-year-old, full of life and so much potential. And I think, "Oh, I hope he doesn't mess it up." Because it's so easy. I was twenty-two, I know – raging hormones, you know. And so, I know. I've been there. They cannot believe that I've been there. [laughs] But it's, you know… Yeah, that's one of the first conversations I have with them, yeah. And I think people who are out there working with young people, whether gay or straight, that that's – the new face of AIDS should be presented. It's – yes, it looks a lot better, but it's still there. There's no cure for it.

RA: And regardless, there's the way the community looked back in the mid-eighties and the way it looks now. Are you – any thoughts on how we actually managed to get to the current state, I would say, health of the community or vitality, from the mid-eighties when things maybe weren't looking so bright? Any thoughts on that?

NM: Within the gay community, I think that it is – it has changed for the better, of course, because of the treatments that are available and how the community sees… Are you asking how the community views AIDS or HIV positive people?

RA: I think, in my way, I'm asking how it managed to spring back. I mean, it's your own opinion whether or not it's stronger – I think you just said that it is – but how did it manage to do that?

NM: I think partly because it's only in times of hardship that a community comes together and works together, and, as unfortunate as it is, that kind of hardship, I think, brought the community together, because there was a common cause that we all were dealing with. And in some ways, I see that today it's a bit more fragmented. Yeah. I… Yeah, there is – that sense is not quite there, I find, of the closeness or the tight-knit community, because – it's good, but being gay has become mainstream. It wasn't back then.

RA: Any other responses… For anybody that has learned from the past, responses today – say politically as well, or other groups that come to mind that somehow have learned from the epidemic and maybe watching the gay community or the health people responding. Anyone else having learned from this and maybe changed the way they do things?

NM: I think that many of the different faith groups have come a long way. I mean, it's not a hundred percent, but many have made changes where places of worship are gay-affirming. And it's happening more and more, and there's more support within that community, so changing quite a bit, which is a good thing, I think. That – that people of faith don't feel stigmatized or feel like the "other," in that you're living in sin, or that kind of stuff. It's – we're not there yet, but it's happening quite a bit, I think, which is good.

RA: What about some of the information sources? During the epidemic – I'm not sure how you worded it but you said something about good information not being available, or facts not being…

NM: Back then.

RA: Back then, yeah. Is any of how we get the facts today somehow related to lessons learned? Is anything done differently?

NM: Um… I think the message that's out there as far as trying prevention – it's a hard message to give out, because people don't… Like I said, the face of AIDS has changed, so people think, "Yeah, it was back then, but now things are different." And so, it's – I think it's a tough one, because people don't see anybody dying of AIDS and what they look like in their last days. And so, I think… It's like smoking – there's all kinds of warnings out there and yet people smoke.

And I think it's the same thing with AIDS. The information is there, but "I'm twenty-two so I'm invincible." Yeah.

RA: That's it for our questions, but at this point are there any things that you might have thought we would ask, or maybe there's some things that are still unsaid that you'd like to share that would add to the picture of this history from that time?

NM: The one thing that I often think about is that when – like I said, I was as ill as I was – just a sheet of skin over my bones. I was completely gone. And the doctor at St. Paul's called me in – I could barely make it to the hospital that day – and said that there's this new treatment that's available now and it's very promising. And I had sort of made peace with myself. I thought I'm not going to live, because at that point there was no way – there was no way. I mean you would have had to dig me out of the grave. That's where I was at the time. And he said, "There's this new treatment available now." It so happened that at that time, he had a pharmacy student with him in the office, and he asked, and I was fine that she sat there. And so, I – I said, "No, I don't want it." And he said, "Well, you know, it's a really good drug and we've had some promising results. But there's no guarantee of course," because it was relatively new. And, I thought, well, why do I have to prolong this? For what? I just want to go. And I said, "No, I don't want to take the drugs. I'm done." And he tried to kind of persuade me, and I declined.

And then he had a phone call, so he stepped out of the office, and the student that was sitting there – I wish I could meet her today; I don't know where she is – the most soft-spoked, timid, kind person. And she said, "You should try this. It is really good. It will work for you." Like, almost guaranteeing that it will work. And I'm thinking, well, how can you say that? But she was really good. And I don't know what happened. The doctor came back, and he said, "You know, these are not cheap drugs, and so I can't give them to you and then you not take them, and I can't force them into your mouth. So, I don't know what else to do." So, I said, "I'll take them." Like, I don't know why I said that. I don't know. I just said, "Okay, I'll take them." That was the last week of November of '96. December 18th… I was bedridden. I could barely get to the hospital. I was taking 300 milligrams of morphine every single day.

The last week of November, I started the drug with a zero CD4 count. December 18th, I was delivering Christmas hampers to the homeless in a snowstorm. Three weeks. So, I will never forget that, and I don't know why I did that at the time when the doctor said, and I said, "Yeah, I'll take it." And the drugs were such a blessing, and it was just a total turn around in my health. Imagine: bedridden and then out there in a snowstorm.

RA: Amazing.

NM: Yeah. So…

RA: Unfair question: what was the drug? Do you remember?

NM: Oh, yeah. Yes. It was a combination of three things: Crixivan, and d4T, and 3TC. Those were the three drugs – the only drugs at the time.

RA: Ill-effects as well, or…?

NM: Oh, yes.

RA: But still, you were delivering parcels in a snowstorm.

NM: Mostly it was gut issues that the Crixivan did, and – but, hey, I was not dying anymore. So, it – and that in itself was an adjustment. "Okay, I'm not going next week. I'm still around and I don't know how much longer now it's going to be." So, that was again, an adjustment within myself, that, okay, I can't give up on life. I have to live it now. And now what?

RA: You mentioned a lot of things where what you do or how you react to other people was effected by a sense of not knowing how long you're going to make it. So, after that fateful moment in the doctor's office and trial run of the snow storm and whatever else – any changes start happening whenever after that for you, in terms of how you reacted to others in the world? Things you did or would picture yourself doing?

NM: I have – like I said even before, when I went to Somalia – and this will sound like I'm bragging but it is what it is. I have always been involved in a lot of volunteering in many ways. And after that fateful moment in – in '96, and all that – it has even given me more sense of giving back. And I – I try to do as much as I can. Like, you know, so'96, I – so, '97, '98, I was fine and then 2001 I went to Afghanistan. Actually, the end of this month, I was supposed to go to India to work with the street kids and volunteer at the AIDS hospice, but I had to cancel my trip because my mother is not well, so – it's not a good time for me to leave her, so I had to cancel it.

RA: One thing I didn't probe about is actually activism. I mean, there are different ways of responding to the epidemic. You mentioned many – not activism. Your experience of that – did you – were you involved with anything of that sort, or did you have friends.

NM: That – no. That – I don't have an ounce of activist bone in me. It's not me – I'm not – I can't do rah, rah, rah. It's not me. So, I have never been involved in anything like that.

RA: Okay. I didn't want to let that go without me making sure.

NM: It's just – it's not my makeup, I don't know.

RA: Then anything else? That was an amazing story, actually, regarding the – taking that new drug, for example – combination of drugs. Anything else that you might want to share?

NM: If – staying with the drugs, I mean, yeah, those were life-saving drugs – they certainly gave me life – but they were nasty. They were toxic. But now, I take two pills a day that don't do a thing to me. I'm just fine. There's no side effects, there's nothing. Yeah, so, my viral load in '96 when it was what it was to a month later, it was undetectable. Like, it was that fast. And my CD4 count went from zero to sixty and then its kept going up to normal levels now. And so, I have been undetectable and – with a high CD4 count since '96, '97. So, it's – and the new drugs are so good. They – they don't cause any side effects or ill effects, so they've come a long way – a very long way.

RA: Actually, with other generations, do you run into, "Drugs? What drugs? Undectectable? What does that mean?"

NM: Yes. I – yes. That has happed. Like, I would say undetectable and then I'd try to explain to them cautiously, because I think, oh, this will – don't think, "Oh, this will give me a license," you know. But – yeah. Yes, many do not know – "CD4 count. What is that?" Yeah.

RA: Anything else, then, that you would want to share that we haven't asked… related to the epidemic, lessons learned, your experience of how things have changed? Any of that?

NM: Nothing kind of pops up, no. I can't think of anything really. It's just, one thing is that I think that, as hard as it is in this day and age to preach the message of prevention, it should be reinforced because there's… It's sad, I think, in a way, because we are losing a generation – a young generation – because of the drug abuse and the abuse that leads to reckless sex. And I think that – that message really needs to… I'm just shocked at the amount of – of the drugs that are out within the community, and it's not just here, it's everywhere. And I see, like, like over the last ten years, I would see a younger person looking as they do, and then eight years later, they look older than I am. And it's all that kind of constant abuse of drugs, and I'm thinking this whole generation that's – we're losing this battle, I think. And it's hard to preach that message of, you know, prevention, but I think we should try harder with that, because obviously we're not – we're not making a mark as far as getting that message out, because there's a lot of it. And that's the one thing I think would be a shame, if that happens – that it continues to happen.

RA: Well, thank you for answering all of these questions and sharing your experience of all of this and your analysis of what you've experienced as well. Thank-you very much.

NM: Sure.

[End, 1:19:55]